



**Maternal and Child Health Services  
Title V Block Grant**

**State Narrative for  
Maryland**

**Application for 2013  
Annual Report for 2011**



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## **I. General Requirements**

### **A. Letter of Transmittal**

The Letter of Transmittal is to be provided as an attachment to this section.

***An attachment is included in this section. IA - Letter of Transmittal***

### **B. Face Sheet**

The Face Sheet (Form SF424) is submitted when it is submitted electronically in HRSA EHB. No hard copy is sent.

### **C. Assurances and Certifications**

The required assurances and certifications have been signed by Ms. Bonnie S. Birkel, Director of the Center for Maternal and Child Health and housed in the Center for Maternal and Child Health's central offices. The assurances and certifications will be made available to the Maternal and Child Health Bureau upon request.

### **D. Table of Contents**

This report follows the outline of the Table of Contents provided in the "GUIDANCE AND FORMS FOR THE TITLE V APPLICATION/ANNUAL REPORT," OMB NO: 0915-0172; published January 2012; expires January 31, 2015.

### **E. Public Input**

The public was invited to review a summary MCH plan for 2011 and to comment on the State's current MCH priorities and performance measures through a web based survey. The survey tool will remain available for public comment throughout the coming year. Survey results will be reviewed and compiled bi-monthly to assist in identifying emerging MCH needs. Comments and recommendations generated by the survey will be considered for incorporation into MCH needs assessment and planning efforts over the next five years. Comments will be summarized and included in next year's application. Links to both the needs assessment and the 2011 application will be available on both the CMCH and OGCSHCN Web sites.

For the Title V Needs Assessment, copies of a 15 page summary of the needs assessment process and the eight selected priority needs were distributed to 200 MCH stakeholders participating in the stakeholder survey and stakeholder meeting and to the Parents Place listserv. Responses thus far have been received from 25 individuals representing a broad range of groups including state agencies, the Maryland Academy of Pediatrics (MD-AAP) and local health departments.

Parents of CSHCN from The Parents' Place of Maryland were participants in preparation and review of the CSHCN portions of the block grant application.

Comments have been incorporated into the needs assessment report. Additional input will be sought through regional meetings in the fall.

/2012/ The online survey was updated for the 2012 application and stakeholders were asked to review the State's Plan for 2012 and to comment. In addition, the Department of Health and Mental Hygiene sought comment on the State's proposed Health Improvement Plan for 2011-2014. Many of the objectives in the Plan align with current Title V performance measures and indicators. A summary of the public comments will be provided at the MCHB meeting in August.

***/2013/ This year, the Title V MCH struggled to find effective ways to reach a broad consumer audience to provide input in to the Block Grant's programs and services. A link was posted on the Facebook page of the Department of Health and Mental Hygiene's web site. Visitors to Facebook are then directed to the Maryland MCH web site and offered an opportunity to provide feedback and comments. The Program will report on findings at the August review meeting. In the future, the Program will examine the feasibility of posting opportunities to comment in local newspapers and newsletters. //2013//***

Additionally, the Adolescent Health and State PREP Program coordinators will be working with the Youth Coordinator in the Center for Adolescent Health at the Johns Hopkins School of Johns Hopkins Bloomberg School of Public Health to develop a State level (and possibly regional )Youth Advisory Council(s). The Councils will provide an important opportunity to receive feedback and input from youth on programs and services offered by Title V.

***/2013/ Public input on Maryland's Title V CYSHCN activities is provided on an ongoing basis through several mechanisms. A close working partnership between OGCSHCN and Maryland's Family to Family Health Information Center, The Parents' Place of Maryland (PPMD) allows constant family and consumer input. OGCSHCN and PPMD jointly lead Maryland's Community of Care Consortium (CoC), a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems, which meets quarterly. OGCSHCN regularly updates and solicits feedback from this group on all Title V CSHCN activities, creating a feedback and planning loop between OGCSHCN and Maryland CYSHCN stakeholders that has proven to be invaluable to the work of Title V CSHCN. For more information on how public input provided by the CoC and PPMD plays a key role in Title V CSHCN please see the narrative discussions on National Performance Measures 2,3,4,5, and 6 and State Performance Measures 6, 7, and 8; as well as the Agency Capacity section dealing with OGSHCN. Specific to the 2010 Block Grant report and 2012 Block Grant application, public input was provided on the sections for CYSHCN by the staff of The Parents' Place of Maryland, and a summary of the Block Grant report sections dealing with CSHCN was presented at the July 27, 2011 CoC meeting. /2013/ The quarterly reporting and feedback from the CoC continues, as does the partnership with PPMD. Public input was once again be provided by PPMD and the CoC for the 2013 Block Grant application. Two new CYSHCN consortiums were started during this past year - one for the Mid-Shore region of the Eastern Shore, and a Latino Consortium in the Capital Area region. These two Consortiums will be approached for public input during this coming year. Additionally, stakeholder input was integral for the revision of state regulations for Maryland's newborn screening programs and for the development of new regulations for screening for critical congenital heart disease (CCHD.) Representatives from local health departments, professional societies, academic centers, parents, March of Dimes, and pediatric providers are participating in the revision and development processes.//2013//***

## II. Needs Assessment

In application year 2013, Section IIC will be used to provide updates to the Needs Assessment if any updates occurred.

### C. Needs Assessment Summary

#### OGCSHCN

In response to findings about Maryland's children with special health care needs (CSHCN) population from the 2010 Title V Needs Assessment, Maryland's Office for Genetics and Children with Special Health Care Needs (OGCSHCN) has made several structural changes to best meet the state level priorities for CSHCN (see the narratives for state performance measures 6, 7, and 8 for more information, as well as the Agency Capacity section dealing with OGCSHCN.) During the second half of 2010 and in 2011, OGCSHCN continued data analysis activities and an error in the preliminary data analysis of the 2010 Maryland Parent Survey, conducted for the 2010 Title V Needs Assessment, was discovered. The analysis in question had been performed by a graduate student at Johns Hopkins University under the direction of a professor in the Bloomberg School of Public Health, who was under contract to conduct the analysis with Maryland's Center for Maternal and Child Health. While OGCSHCN and The Parents' Place of Maryland (PPMD)- who conducted the survey - were completing additional analysis activities, the error with the Johns Hopkins analysis was discovered. An incorrect denominator was used and this resulted in a roughly 2% under-reporting rate for certain characteristics of responding families with at least one child or youth with special health care needs (CYSHCN.) Corrections can be found in Maryland's 2012 Block Grant application Needs Assessment section.

***/2013/ OGCSHCN continues to use the 2010 Title V Needs Assessment to guide program planning and implementation. No major demographic or policy changes have occurred that will impact the findings; however Maryland is moving forward with health care reform and OGCSHCN monitors this progress to keep abreast of relevant changes that affect our target population. State priorities for CYSHCN include strategic partnerships, data systems and sharing, and youth transition to adulthood. For more on each of these priorities, please see the narrative sections for State Performance Measures 6, 7, and 8 in this document. OGCSHCN continues to report plans and progress around each of these priorities to the Maryland Community of Care Consortium (CoC).***

***OGCSHCN continues to conduct ongoing needs assessment activities. This year, activities focused on newborns with Critical Congenital Heart Disease and on children and youth with autism and other developmental disabilities. The Maryland General Assembly mandated in 2011 that a legislative report be written on the feasibility of implementing newborn screening for Critical Congenital Heart Disease (CCHD) in Maryland. OGCSHCN's Medical Director coordinated the efforts of the Advisory Council on Hereditary and Congenital Disorders to research and write this report and was actively involved in these efforts. The report was submitted to the legislature in December 2011 and identified the following needs related to newborn CCHD screening: education of the public and community providers; education and support of birthing facilities and providers performing screening; and expansion of the capacity of OGCSHCN to provide surveillance of the screening program and follow up of infants with abnormal screens. Despite these needs, the report found that Maryland was well positioned to begin screening, and the mandate will become effective on September 1, 2012. OGCSHCN will utilize the OZ Systems newborn screening database to fulfill the surveillance and follow-up functions of the screening program.***

***OGCSHCN, in partnership with The Parents' Place of Maryland (PPMD) was awarded a planning grant from HRSA to develop a statewide plan to improve the system of health care and related services for CYSHCN with autism (ASD) and other developmental***

*disabilities (DD). In support of this, OGCSHCN conducted a comprehensive statewide needs assessment of Maryland CYSHCN with ASD and DD. Data sources included national and state secondary data, primary data sources of state agencies and community organizations, a new analysis of the 2010 Maryland Parent Survey, and focus groups with under-represented subpopulations (including Spanish speaking families, families from rural regions of the state, and low income families.) A rough draft of the needs assessment was circulated to state autism leaders and their feedback and edits will be incorporated into the final draft. Regional needs assessments were conducted and presented to stakeholders in each region of the state to use in priority needs and goals identification and action planning. The statewide and regional needs assessments as well as meeting summaries are available on OGCSHCN's and the CoC's ([www.marylandcoc.com](http://www.marylandcoc.com)) websites in early Fall 2012. //2013//*

CMCH

*//2013/Infant mortality reduction, identified as a priority need area in the 2010 needs assessment continues as a challenge. Governor Martin O'Malley has made reducing infant mortality and racial disparities in infant mortality through implementation of the State Plan one of the Administration's 15 strategic goals under the Governor's Delivery Unit (GDU).*

*In 2011, the Center for Maternal and Child Health updated a comprehensive Plan to Reduce Infant Mortality in Maryland, which addresses the many factors related to infant mortality and uses evidence-based approaches. DHMH employed several strategies during 2011 to obtain broad and substantive input regarding infant mortality in Maryland and recommendations obtained through this process are incorporated into the updated Plan. The public input process included:*

- . The Infant Mortality Breakout Session at the Governor's Forum on Children and Health in January 2011;*
- . A meeting with pediatricians from across central Maryland entitled, "The Role of Community Pediatricians in Preventing Infant Mortality";*
- . The Maryland Infant Mortality Epidemiology Work Group, which provided a summary of the latest research on infant mortality and recommendations for reducing infant mortality in Maryland (see their report on-line: [http://dhmh.maryland.gov/babiesbornhealthy/pdf/Plan\\_Reducing\\_Infant\\_Mortality\\_MD\\_Dec2011.pdf](http://dhmh.maryland.gov/babiesbornhealthy/pdf/Plan_Reducing_Infant_Mortality_MD_Dec2011.pdf)); and*
- . A web-based survey completed by 339 Marylanders including 89 consumers/residents, 47 advocates/policymakers and 178 health care workers.*

*A number of valuable strategies and recommendations for reducing infant mortality in Maryland were obtained through public input. The following is a summary of findings from the Governor's Forum, the Pediatricians' Meeting, and the web-based survey.*

#### **Overarching Strategies**

- . Make targeted outreach a defined strategy of the Plan using messaging aimed at important populations that is culturally competent, at the appropriate health literacy level, and uses appropriate venues and media.*
- . Use mass media to deliver consistent messaging on reproductive life planning, Safe Sleep, pregnancy risks, breastfeeding, the importance of prenatal care, the availability of services, etc.*
- . Promote comprehensive, coordinated care between health care providers, hospitals, schools, local health departments, and support services.*
- . Expand home visiting and patient navigator programs (including those that utilize peer educators).*
- . Facilitate real time access to data (including birth records, death records, Pregnancy Risk Assessment forms, hospital and practice-specific outcomes, SUID/SIDS deaths, Fetal Infant Mortality Review, Child Fatality Review, Managed Care Organizations, etc.) to*

*address disparities and inform interventions.*

- . Promote cultural competency among health care providers.*
- . Promote health literacy.*
- . Expand partnerships to include Certified Nurse Midwives, MD State Department of Education, Department of Human Resources, consumers, community organizations and businesses, academic centers, private providers/clinics, health care payors, Federally Qualified Health Centers, and advocates.*
- . Promote evidence-based approaches and quality improvement initiatives, and evaluate outcomes.*
- . Research the causes of health disparities in birth outcomes and the role of fathers, racism, stress, the environment and diet in birth outcomes.*

#### *Before Pregnancy*

- . Support and incentivize through reimbursement comprehensive primary care in a medical home that includes reproductive life planning, women's health, and coordination with support services such as nutrition, exercise, weight management, smoking cessation, behavioral health services, dental care, etc.*
- . Improve access to family planning services (for example through school-based centers, expanding income eligibility, and targeting at-risk groups).*
- . Promote comprehensive sex education in the schools.*

#### *During Pregnancy*

- . Expedite enrollment into Medical Assistance for pregnant women.*
- . Expand access to obstetrician providers by making it easier for obstetricians to take Medical Assistance (particularly on the Eastern Shore).*
- . Incentivize early prenatal care through reimbursement.*
- . Promote Certified Nurse Midwife model and practice.*
- . Standardize obstetrician and hospital practices around testing (prenatal, HIV, and drug screening).*
- . Promote breastfeeding and breastfeeding support services.*
- . Promote smoking cessation resources.*
- . Provide support for transportation, for pregnant women at a minimum.*

#### *Following Delivery*

- . Develop a standard postpartum hospital discharge plan for mothers and infants.*
- . Develop a standardized postpartum discharge referral form for high risk mothers and infants.*
- . Expand postpartum home visiting services and promote streamlined access to and coordination among programs.*
- . Work with pediatricians to address maternal risks (chronic illness, lifestyle issues, family planning, smoking cessation).*

*//2013//*



### III. State Overview

#### A. Overview

Maryland has been aptly described as "America in Miniature." Although a small state in size and population, Maryland has great geographic and demographic diversity. This diversity creates unique challenges for the health care system in Maryland and barriers to care for many Maryland residents. The State is characterized by mountainous rural areas in the western part of the State, densely populated urban and suburban areas in the central and southern regions along the I-95 corridor between Baltimore and Washington D.C., and flat rural areas in the eastern region. The "Eastern Shore" borders Delaware, the Atlantic Ocean and the Chesapeake Bay, the largest estuary in the U.S. The Bay is a treasured geographic asset but the fact that it bisects the state presents special challenges for Eastern Shore residents. Maryland is comprised of 24 political jurisdictions -- 23 counties and the City of Baltimore. Nine of the counties are on the Eastern Shore.

The racial/ethnic distribution of the Maryland population of 5.6 million is equally diverse: White (64.1%), Black or African American (30.0%), Asian or Pacific Islander (5.4%), and American Indian (<1%). Nearly 7% of the population (6.7%) is comprised of individuals of Hispanic origin. Minorities represented 42% of the State's 2008 population of 5.6 million. Latinos continue to be the fastest growing racial/ethnic group, representing over 6% of the State's 2008 population. While nationally, the majority of Hispanics migrate from Mexico, Maryland's Hispanic immigrants are predominantly from South and Central America. Racial/ethnic minorities now represent a majority of the babies born in Maryland (54.2% in 2008). Minority populations in Maryland continue to grow as the State's white population declines. Maryland's undocumented immigrant population is estimated to be 250,000 (Pew Hispanic Center 2008).

The prevalence and impact of health disparities continue to be significant nationally and in Maryland. The 2008 National Healthcare Disparities Report from the Agency for Healthcare Research and Quality states that nationally, 60% of disparities in quality of care measures are either not improving or actually getting worse over time. In Maryland, racial and ethnic minority disparities exist for ten of the 14 leading causes of death. Areas of significant disparity include infant mortality, maternal mortality, child deaths, cardiovascular disease, cancer, diabetes, HIV/AIDS, kidney disease, asthma, health insurance coverage, ability to afford health care, and utilization of mental health services. Maryland's high infant mortality and persistent racial/ethnic disparities in infant mortality continue to be major challenges. In 2008, Maryland's infant mortality rate was 8.0 infant deaths per 1,000 live births, virtually unchanged since 1998 and ranking Maryland 39th in the U.S. African American infant deaths occur at more than double the rate of White, Hispanic, and Asian infant deaths in Maryland.

/2012/ Maryland's infant mortality rate declined to 7.2 infant deaths per 1,000 live births in 2009. However, there was a worsening of the racial disparity between African Americans and Whites.  
//2012//

An estimated 1.2 million of Maryland's 5.6 million residents are women of childbearing age (ages 15-45) according to the most recent U.S. census (2008) estimates. The State's 1.5 million children and adolescents ages 0-19 included: 296,425 young children under the age of five; 361,155 elementary school aged children ages five to nine; and 773,937 adolescents ages ten to 19. Another 377,174 Marylanders were young adults ages 20-24. Senior citizens aged 65 and over, represented 11.4% of the population.

Maryland's workforce is one of the best educated in the nation. Over a third of Maryland's population aged 25 and older held a bachelor's degree or higher in 2008. More than 146,455 businesses employ 2.29 million workers. Of those employed in 2008, 72% of people were private wage and salary workers; 23% were federal, state or local government workers; and 5% were self-employed. Health care represents a \$38.5 billion industry in Maryland with per capita spending on health care reaching \$6,374 in 2007. Hospital care represented the largest category

of expenditures and accounted for one-third of expenditures in 2007.

As one of the wealthiest states in the nation, Maryland had the second lowest poverty rates, both overall and among children in 2008. However, poverty rates in Maryland continue to vary by age, race/ethnicity and jurisdiction. U.S. Census estimates for 2008 indicate that 8.2% of Marylanders were poor. Poverty rates ranged from a high of 23.1% in Somerset County to a low of 4.3% in Howard County. An estimated 137,831 Maryland children ages 0-17 (10.4%) lived in poverty in 2008. By jurisdiction, child poverty rates ranged from a high of 27.9% in Somerset County to a low of 4.9% in Howard County. The state's median household income stood at an estimated \$70,482 in 2008 and by jurisdiction ranged from a high of \$101,876 in Howard County to a low of \$39,426 in Somerset County.

Despite Maryland's continued relative affluence, the current recession has had a profound impact in Maryland, particularly in state government where revenue shortfalls have left a \$700 million budget deficit. As a result, local health department funding was cut by 45% between FY 2009 and FY 2011 which necessitated lay-offs that included local MCH staff. A state government "temporary salary reduction plan" (mandatory furlough days) has been in effect for two years. Health clinicians (physicians, nurse-midwives, nurse-practitioners and physician's assistants) working in state facilities were exempt in FY 2009 but there have been no exemptions in FY 2010 or in FY 2011.

/2012/ Mandatory furlough days ended in State fiscal year 2012. //2012//

Health care workforce shortages/distribution affects many Maryland communities. Twenty-two of Maryland's 24 jurisdictions are currently either entirely or partially federally designated as medically underserved areas for primary care services. These shortage areas exist even though the ratio of primary care physicians to the population is higher in Maryland than the national average. This shortage is thought to be due to the high number of Maryland physicians employed by government research facilities, the military and medical schools in non-direct health care positions. Four of Maryland's 24 jurisdictions are currently classified as being underserved for dental health services/manpower and six jurisdictions are classified as underserved for mental health services. Federally qualified community health centers are located in 18 jurisdictions.

Maryland has 34 birthing hospitals, with only two nurse-midwife operating birthing centers. The distribution and level of care among the birthing hospitals is unusual -- there are 7 Level I facilities, 11 Level II facilities, and 16 Level III facilities. The voluntary Maryland Perinatal System Standards further distinguish the Level III hospitals into Level IIIA, IIIB, and IIIC. All but two of the Level III facilities are in the Baltimore or Washington D.C. metropolitan areas. Maryland's all-payer rate setting system for hospitals, in place for thirty (30) years, is the only such system in the U.S.

In spite of Maryland's relative affluence and significant health care assets, health indicators for the State remain mixed. In the 2009 Kids Count Data Book (Annie E. Casey Foundation), Maryland ranked 25th on ten indicators of child well-being. According to the 2007 National Survey of Children's Health, the prevalence of children aged 0-17 years who have special health care needs is 20.1% in Maryland, higher than the national prevalence of 19.2%. Obesity and obesity-related illnesses such as type 2 diabetes are documented to be increasing among children and adolescents. The 2005 needs assessment reported that health providers and school health personnel were increasingly identifying depression and mental health disorders as problems among adolescents. In the 2010 needs assessment, these same health concerns continue to affect Maryland children.

/2012/ Maryland continued to rank 25th in the 2010 Kids Count Data Book. //2012//

However, progress has been made on many fronts. Fewer women are smoking during pregnancy and more are initiating breastfeeding in the early postpartum period. Teen birth rates as well as child and adolescent death rates continue to decline. More children are being screened for lead exposure and fewer are being found with elevated blood lead levels. There are

fewer uninsured children and more young children are being fully immunized. Fewer adolescents are smoking and juvenile arrests for violent crimes are down. More detailed MCH-related health status indicators are reported on in the other Narrative Sections and/or the Health Status Indicator Section. Emerging health trends, problems, gaps and barriers are also identified in the 2010 Needs Assessment Report.

#### State Health Priorities

/2012/ The Maryland Department of Health and Mental Hygiene is currently developing a State Health Improvement Plan (SHIP) for 2011-2014. This Plan will provide a framework to support improvements in the health of Marylanders and their communities. It includes measurable objectives and targets in key areas of health, with a special focus on health equity. There are currently five draft focus areas: 1. Improve reproductive health care and birth outcomes; 2. Ensure that Maryland indoor and community environments are safe and support health; 3. Prevent and control infectious disease; 4. Prevent and control chronic disease; and 5. Ensure that all Marylanders receive the health care they need. Organizers are currently reviewing public comments and the final Plan is scheduled to be released in late July. Local and regional coalitions will be formed to develop local implementation plans aimed at achieving SHIP objectives of regional and local priority. //2012//

In August 2009, Governor Martin O'Malley identified the reduction of infant mortality by 10% by 2012 as one of the State's top 15 strategic policy goals through an initiative termed the Governor's Delivery Unit (GDU) Plan. The GDU Plan for infant mortality reduction builds on the State's Babies Born Healthy Initiative by expanding prevention services, improving infrastructure, and building new models and systems of care. Initially, three jurisdictions (Baltimore City, Prince George's and Somerset Counties) with high infant mortality rates and racial disparities have been targeted. The DHMH Center for Maternal and Child Health (CMCH) is the lead agency with collaboration from other DHMH programs including the Office of Minority Health and Health Disparities, Medicaid, the Alcohol and Drug Abuse Administration, the Mental Hygiene Administration, WIC, and the local health departments in the three target jurisdictions, as well as the Department of Human Resources (DHR) and the Governor's Office for Children.

/2012/ Governor O'Malley was elected to a second term in November 2010. In January 2011, Dr. Joshua Sharfstein replaced John Colmers as the Health Secretary. //2012//

/2012/ Dorchester County was added as a GDU county in 2011. //2012//

The Governor's initiative builds on the Babies Born Healthy Initiative using a life course approach for implementing programs and services to address the needs of women and infants prior to, during and following pregnancy. Family planning services are being expanded in target jurisdictions to a broader Comprehensive Women's Health model, with the goal of healthier women prior to and between pregnancies. Medicaid, in collaboration with DHR, has established a new Accelerated Certification of Eligibility (ACE) enrollment process at both local health departments and local departments of social services. Medicaid coverage for pregnant women begins within 48 hours of an abbreviated application process and continues up to 90 days while a full Medicaid application is completed, with a goal of earlier entry into prenatal care. "Quickstart" prenatal care services have been established in the target jurisdictions with expanded screening and referral services and deployment of community outreach workers, with a goal of risk-appropriate early prenatal care. A standardized post-partum discharge referral process for birthing hospitals statewide is being piloted in the three target jurisdictions, assuring coordination between hospitals, providers, local health departments and community services, with a goal of risk-appropriate follow-up services for mothers and infants. Promoting "Safe Sleep" is a key component.

Access to oral health care remains a priority for Maryland children and families. Maryland efforts to create an oral health safety net have increased significantly as a result of the tragic death of Deamonte Driver, a 12 year old Prince George's County resident, from an untreated dental abscess. This sentinel event occurred in February 2007 amid already growing concern about

inadequate access to dental care. In response, DHMH Secretary John Colmers established a Dental Action Committee (DAC) which made seven major recommendations with a goal of establishing Maryland as a national model for children's oral health care. In response to DAC recommendations, the Maryland General Assembly approved an appropriation of \$14 million (annually) to increase Medicaid dental rates to enhance the dental public health infrastructure and increase access to dental public health services for low-income children. Six new public health dental clinics have been established in regions of the State where there had been no dental public health program or facility. Support for school-based dental programs has been increased. By the end of 2010, residents in every Maryland jurisdiction will have access to a safety-net or school-linked dental clinic. Since July 2009, EPSDT medical providers including pediatricians and nurse practitioners are allowed reimbursement for the application of fluoride varnish to very young children not currently being seen by dentists.

/2012/ The Dental Action Committee transitioned to the Dental Action Coalition. This May, the Coalition along with the Health Secretary and others published the State's first five year Oral Health Plan. In addition, Maryland was named as the top performing state in the nation for children's oral health by the PEW Trust. //2012//

Lack of health insurance coverage remains a barrier to health care for an estimated 12.9% of all Maryland residents; 9% of children and adolescents ages 19 and under are uninsured. The Medicaid Program, known in Maryland as the Medical Assistance Program, serves as the major source of publicly sponsored health insurance coverage for children and adolescents. The Maryland Children's Health Program (MCHP) began operating as a Medicaid expansion program on July 1, 1998. The MCHP program expanded comprehensive health insurance coverage to children up to the age of 19 with family incomes at or below 200% of the federal poverty level (FPL). In 2001, Maryland initiated a separate children's health insurance program expansion, MCHP Premium. In FY 2008, 359,039 children and adolescents were enrolled in the Medicaid Program at some point during the year, while 120,906 were enrolled in MCHP. MCHP also provides insurance coverage for pregnant women with incomes between 185% and 250% of the federal poverty level. In FY 2008, Medicaid covered hospital delivery costs for approximately one-third of Maryland births.

Over the last three years, Maryland has expanded access to health insurance coverage to more than 161,000 Marylanders, 78,500 of whom are children under the Working Families and Small Business Health Coverage Act. The Act extends Medicaid coverage to parents and other family members caring for children with incomes up to 116% of the federal poverty level. On July 1, 2008, Medical Assistance benefits expanded to include comprehensive health care coverage for many more parents and other family members caring for children. Eligibility depends on family size and income. The income limit is about \$21,200 for a family of three. There is no asset limit when applying, no face-to-face interview is required and there are options to apply online, by mail or by fax.

/2012/ Legislation passed in 2011 extends Medicaid coverage for family planning services to women with family incomes between 116% and 250% of the federal poverty level. This expansion is projected to extend eligibility to an additional 30,000 women when it becomes effective on January 1, 2012. //2012// **/2013/ To date, the expansion program has enrolled approximately 2,000 women. //2013//**

**/2013/ Legislation passed in 2012 requires the Maryland Insurance Commission to convene two advisory groups -- one to review access to habilitative services for all children and the other to review coverage for autism specific services for children. OGCSHCN will have representation in these advisory groups. //2013//**

Reducing health disparities continues to be a major priority in Maryland. In a memo sent to all DHMH employees on April 14, 2010, Secretary Colmers reiterated Maryland's commitment to addressing disparities, stating: "As Maryland prepares to implement health care reform, it is essential that we confront the disparities that plague far too many members of our minority communities. Eliminating disparities in health access and outcomes are a critical part of the DHMH mission and our day-to-day operations." The DHMH Office of Minority Health and Health

Disparities (OMHDD), was established in statute by the 2004 General Assembly through enactment of House Bill 86. OMHDD has been directed by Carlessia Hussein, RN, DrPH since its inception. Dr. Hussein reports directly to Secretary Colmers, and OMHDD serves as a resource for training and consultation on minority health issues and cultural competence throughout the department, for local health departments, and for community-based organizations. OMHDD has primarily focused its efforts in the areas of cancer and tobacco which reflects a major funding source, the Cigarette Restitution Fund. OMHDD has had a number of accomplishments from its early work to reduce smoking and cancer disparities; the all-cause cancer mortality disparity was reduced by over 50% between 2000 and 2005. In 2008, OMHDD joined CMCH as a partner in the Babies Born Healthy Initiative, and more recently has become a major partner in Governor O'Malley's Infant Mortality Initiative. CMCH partners with OMHDD to address asthma disparities.

/2013/

***Improving health care quality and controlling health care costs remain priorities. The Maryland Health Quality and Cost Council, chaired by the Lt. Governor and the DHMH Secretary, was established by executive order in 2007 to develop recommendations for improving health care quality and reducing health care costs in the State. In 2009, the Health Quality and Cost Council recommended the promotion of Healthiest Maryland, a Statewide movement to create a culture of wellness--an environment that makes the healthiest choice an easy choice. The three components of Healthiest Maryland are Healthiest Maryland Businesses, Healthiest Maryland Communities, and Healthiest Maryland Schools. Within each of the sectors, there is a peer-to-peer recruitment campaign to engage leadership and conduct an organizational assessment, referral to resources and technical assistance, and recognition of successful implementation of policies and environmental change. In addition, corresponding State-level policies and environmental changes will contribute to the culture of wellness throughout Maryland.***

***The Health Quality and Cost Council has identified obesity prevention as a major priority and is working with the DHMH Office of Chronic Disease Prevention (OCDP) to develop policies to promote access to healthy foods and opportunities for physical activity, particularly for populations who experience health disparities or who are at vulnerable periods in the life course. Black, Hispanic, and low-income Marylanders have higher rates of obesity, poor diet, and physical inactivity. Instilling healthy lifestyle habits in childhood is one way of forestalling the rising rates of child and adult obesity. Women of childbearing age are another important population because a growing body of evidence demonstrates a link between fetal exposures and risk for obesity in adulthood. Three specific Healthiest Maryland objectives that are related to maternal and child health are: promoting workplace wellness in industries that employ women of childbearing age, promoting lactation support in the workplace, and promoting implementation of wellness policies in licensed child care and schools. CMCH and the Maryland WIC program are partners with the Office of Chronic Disease Prevention on breastfeeding promotion and childhood obesity prevention.***

***/2012/ Under the leadership of the Office for Chronic Disease Prevention, Maryland recently applied for a federal Community Transformation Grant to prevent and control obesity, hypertension and diabetes in at risk communities. If successful, grant funds will be used to build on components of the Healthiest Maryland Initiative. //2012//***

***In March 2010, the Governor created the Maryland Health Care Reform Coordinating Council to advise the administration on policies and procedures to implement recent and future federal health care reform legislation. The Council will make policy recommendations and offer implementation strategies to keep Maryland among the leading states in expanding quality, affordable health care while reducing waste and controlling costs.***

***/2012/ The Council released its final recommendations in January 2011. The 2011 Maryland Legislature outlined a plan for moving forward with health care reform efforts in***

**Maryland including Maryland's approach to the Health Benefit Exchange requirement.  
//2012//**

**The Family Health Administration's priorities will continue to focus on strengthening programs, as well as revitalizing public health data systems, building public health partnerships (with the academic centers, professional and advocacy groups, and others), and strengthening operational aspects of public health administration (e.g., budget, personnel, procurement, legislation, information technology). In addition, a major FHA focus will be on leadership development with special attention paid to developing and mentoring the next generation of public health leaders.**

#### **MCH/CSHCN Program Priorities**

**Priorities for the Maryland Title V Program are aligned with the state priorities described above. Priorities reflect the ongoing needs assessment process and are determined in partnership between the Center for Maternal and Child Health (CMCH) and the Office for Genetics and Children with Special Health Care Needs (OGCSHCN) in collaboration with sister programs within the Family Health Administration (FHA), other units within DHMH, other state agencies and stakeholders. There are many services for CSHCN available in the State and the OGCSHCN provides funding to a significant portion of them. The OGCSHCN and its partners work to create and sustain a community-based, coordinated, family-centered, culturally competent system of health care and related services for children and youth with special health care. Current priorities are:**

**•Reducing infant mortality and racial disparities in birth outcome: Despite ongoing fiscal constraints, both the Governor and the Legislature have maintained state funding for the Babies Born Healthy Initiative. As noted above, Babies Born Healthy funding supports a new Governor's Initiative to reduce infant mortality in Maryland by 10% by 2012.**

**•Assuring access to family planning services: This includes assuring that the program maximizes efficiencies and minimizes costs while continuing to offer convenient no cost/low-cost services through a diverse network of providers, to reach more women in need. This is to be done without sacrificing the current level of comprehensiveness or quality of services. Family planning is a strategy for reducing infant mortality, and serves as the base for expanding services under the Governor's initiative.**

**•Advancing new prevention priorities in the areas of environmental health: This includes improving asthma management and promoting healthy nutrition/physical activity to address obesity and overweight across the life span. CMCH is the recipient of a CDC asthma intervention grant and also is responsible for administering the legislatively mandated Asthma Control Program.**

**•Early Childhood Comprehensive Systems (ECCS): CMCH administers the MCHB ECCS program and works in partnership with many state agencies in systems building activities. On July 9, 2010, CMCH submitted an application for the new Section 511 Maternal, Infant, and Early Childhood Home Visiting Program. This new federal funding will provide important support for a more fully integrated system of care aimed at improving outcomes for families.**

**/2012/ Maryland completed the home visiting needs assessment and submitted applications for 2010 and 2011 funding. The State also applied for competitive developmental funding. //2012//**

**/2013/ This year, with support from advocates, home visiting providers, state agencies, policy makers and families, the Maryland Legislature passed the Home Visiting Accountability Act of 2012. This Act requires that State funding allocated for home visiting only support evidence based programs or promising practices. Pew recently held a celebration to recognize passage of the Act and called Maryland's system one of the**

***best in the nation for investing home visiting dollars effectively. //2013//***

•Adolescent health systems development: This is a developing priority for both CMCH and OGCSHCN. CMCH hopes to partner with OGCSHCN, perhaps using a model similar to SECCS, to develop a comprehensive inter-agency approach for improving adolescent health. /2012/ CMCH applied for and is currently administering both Abstinence Education and Personal Responsibility and Education Program (PREP) funds made available under the Affordable Care Act. //2012//

•Strategic planning: During the coming year, CMCH and OGCSHCN will collaborate on refining the five year MCH strategic plan based on the MCH Needs Assessment, with further input from local health departments, health providers, family groups, community-based organizations, advocacy groups and other MCH stakeholders.

•Epidemiological capacity: Maryland continues to face substantial gaps in data needed to assess and monitor the health of its women and children. Recommendations for additional surveillance are included in the MCH Needs Assessment.

•Strategic partnerships: In order to address CSHCN core outcomes in Maryland, the Maryland Community of Care Consortium (CoC), initiated through the D70 grant, has created a broad alliance of diverse stakeholders to improve systems of care for Maryland CSHCN and their families. Multiple State agencies, academic and community providers of every sort, families, professional organizations, CYSHCN focused voluntary groups and community groups are engaged in collaborative efforts. In the past year, the OGCSHCN and the CoC have worked together to identify strategies in support of action plans for the state to strengthen partnerships, youth transition, and data systems within the system of care for CYSHCN. In addition, OGCSHCN has expanded partnerships with other government and community agencies. Enhanced or new relationships include the Maryland Health Care Commission, the Maryland Developmental Disabilities Council, and the Maryland Center for Excellence in Developmental Disabilities. ***/2013/ OGCSHCN is forging new partnerships with Maryland's Mental Hygiene Administration around telehealth in rural regions of the state and with Maryland State Department of Education around the early childhood Race to the Top grant around developmental screening. Additionally, OGCSHCN participated in the development of two new consortia for CYSHCN in the state -- one in the rural MidShore section of the Eastern Shore region and one for Spanish speaking families and community service providers. //2013//***

•Successful transition of all youth to adulthood: The OGCSHCN and its partners will work to improve the supports for CYSHCN approaching transition, beginning with supports for transition planning. Currently, Maryland lags behind the nation; ranking 40th in the nation with only 36.8% of Maryland families of YSHCN aged 12 to 17 reporting that their child received the services necessary to make appropriate transitions to adult life. In the past year, OGCSHCN has created a Transition Coordinator position, has joined Maryland's Interagency Transition Council, and has partnered with the Maryland State Department of Education on multiple initiatives related to youth transition to adulthood. OGCSHCN has also developed the parent survey around youth transition issues that will be administered each year for the next five years to provide data for this priority's outcome measure. ***/2013/ OGCSHCN, in partnership with The Parents' Place of Maryland (PPMD), held 3 Health Care Transition conferences in different regions of the state to provide training and resources for families and YSHCN on health care transition. OGCSHCN conducted the first yearly Transitioning Youth Parent Survey. The OGCSHCN Transition Coordinator is developing a strategic plan to address health care transition in Maryland and is forming partnerships with other agencies and organizations throughout the state to contribute to the development and implementation of the plan. //2013//***

•Improve Data Systems and Sharing: Improve state and local capacity to collect, analyze, share, translate and disseminate MCH data and evaluate programs. Maryland collects state and

jurisdiction level data that would be useful to analyze and evaluate on behalf of the population of CYSHCN and other maternal and child health populations. By developing data sharing plans between agencies, Maryland will better target efforts to improve systems of care for CYSHCN and to provide timely information to stakeholders. OGCSHCN has established several data-sharing agreements with other state agencies during the past year. ***/2013/ OGCSHCN hired a new Database Administrator which has significantly improved the capacity for building and linking data systems within programs in OGCSHCN as well as building relationships with DHMH's Department of Information Technology. Development of a statewide resource database is underway. //2013//***

/2012/ By 2012, the Title V Program plans to designate a Life Course Theory (LCT) Coordinator. Along with the SSDI Project Coordinator, the Life Course Coordinator will work with key MCH staff to facilitate integration of the life course model into Title V programming. A Life Course Data Workgroup will be formed to facilitate a broader, more integrated, life course approach to using data to design, implement and measure programs and policies, and eventually, making such data available to stakeholders. Workgroup members will invite the participation of partners within and outside DHMH and LCT metrics will be piloted and tested for the 2015 Needs Assessment. //2012//

Other health priorities for the State are childhood injuries, asthma, lead, obesity, depression and other mental health disorders. Injuries remain the leading cause of child and adolescent deaths. Two major environmentally linked health conditions--asthma and lead poisoning--continue as major causes of childhood morbidity. An estimated 190,000 Maryland children and adolescents have asthma. In 2007, the Maryland Legislature passed the Clean Indoor Air Act which prohibits smoking in most workplaces and resultantly reduces exposure to second hand smoke, a contributing factor to asthma for some Marylanders. In 2008, 106,452 children between the ages of 0-72 months were tested for lead exposure. Of those children, 489 (0.5%) had elevated blood lead levels of  $\geq 10$  ug/dL. Much of the decline in blood lead levels is the result of implementation and enforcement of Maryland's "Reduction of Lead Risk in Housing" law. The law requires each pre-1950 rental dwelling to be issued a Full Risk Reduction certificate at tenant turnover.

## **B. Agency Capacity**

Both the Center for Maternal and Child Health (CMCH) and the Office for Genetics and Children with Special Health Care Needs (OGCSHN), hereafter referred to collectively as the "MCH Program," share responsibility for MCH Block Grant development and implementation. The MCH Program operates within the DHMH Family Health Administration which is also home to the Maryland WIC program, the Office of Chronic Disease Prevention, the Center for Health Promotion and the Office of Oral Health. Much more about the MCH Program and other agencies within FHA can be found at <http://fha.maryland.gov>. The MCH Program works with state and local agencies to ensure coordination of services for all women and children, but particularly those with limited access to care.

The mission of the Maryland's MCH Program is to protect, promote and improve the health and well-being of women, children and adolescents, including those with special health care needs. Major goals include improving pregnancy and birth outcomes, improving the health of children and adolescents, including those with special health care needs, assuring access to quality health care services, eliminating barriers and health disparities, and strengthening the MCH infrastructure. MCH programs and services in Maryland are provided at each of the four levels of the MCH pyramid to protect and promote the health of women and children, including those with special health care needs. Both CMCH and OGCSHCN work collaboratively to ensure that Title V funds are administered efficiently and according to best practice standards in public health.



The MCH Program is responsible for addressing several federal and state mandates for improving the health of women and children. State statutes and regulations relevant to the capacity of the Title V MCH Block Grant Program include the following:

Diseases of Pregnancy and Childhood (Health-General Article, SS18-107, Annotated Code of Maryland) -- Directs the Secretary to devise and institute means to prevent and control infant mortality, diseases of pregnancy, diseases of childbirth, diseases of infancy, and diseases of early childhood as well as to promote the welfare and hygiene of maternity and infancy. This mandate applies to programs administered within CMCH and OGCSHCN.

Child Fatality Review Teams (Health-General Article, SSSS 5-701 et seq., Annotated Code of Maryland) -- Establishes multidisciplinary, multi-agency State and local child fatality review teams for the purpose of preventing child deaths. Administrative support is to be provided by the CMCH.

Maryland Asthma Control Program (Health-General Article, SSSS 13-1701 et seq., Annotated Code of Maryland) -- Establishes the Maryland Asthma Control Program within DHMH. The Program is administratively housed within CMCH.

Maternal Mortality Review Program (Health-General Article, SSSS13-1201 et seq., Annotated Code of Maryland) -- Establishes a program to review maternal deaths in partnership with MedChi (the State Medical Society) and provides certain immunity from civil liability and criminal disciplinary actions. Support is provided to MedChi by CMCH.

Children's Environmental Health and Protection Advisory Council (Health-General Article, SSSS13-1501 et seq., Annotated Code of Maryland) -- Creates a Council which is charged with identifying environmental hazards that may affect children's health and recommending solutions.

Lead Poisoning Screening Program (Health-General Article, SS18-106, Annotated Code of Maryland) -- Establishes a Lead Poisoning Screening Program to assure appropriate screening of children. This Program is administratively placed within CMCH.

School Health Program (Education Article, SS7-401, Annotated Code of Maryland) -- Requires the State Department of Education and the Department of Health and Mental Hygiene to jointly (1) develop public standards and guidelines for school health programs; and (2) offer assistance to the county boards and county health departments in their implementation.

Child Death Review (House Bill 705 (2009) -- Child Fatality Review - Child Death Review Case Reporting System (codified at Health-General Article, SSSS5-701 and 5-704, Annotated Code of Maryland)); COMAR10.11.05 Child Death Review Case Reporting System) -- Authorizes the members and staff of the State Child Fatality Review Team to provide identifying information related to cases of child death in Maryland to the National Center for Child Death Review (NCCDR). The information transfer will occur in accordance with a data use agreement that requires the NCCDR to act as a fiduciary agent of the State and local Child Fatality Review Teams. The bill also outlines the confidentiality and discovery protections related to information provided to the NCCDR. CFR was established by statute in 1999 with enactment of Senate Bill 464.

Fetal and Infant Mortality Review (House Bill 535 (2008) -- Morbidity, Mortality and Quality Review Committee (codified at Health-General Article, SS18-107, Annotated Code of Maryland)); COMAR 10.11.06 Morbidity, Mortality, and Quality Review Committee -- Pregnancy and Childhood) -- Protects Fetal and Infant Mortality Review (FIMR) records from being released in a legal action and provides FIMRs immunity from civil liability and criminal disciplinary actions; establishes an infrastructure to coordinate FIMR with other related reviews such as Child Fatality Review, Maternal Mortality Review, and other reviews of morbidity and mortality associated with pregnancy, childbirth, infancy, and early childhood.

Lead Poisoning Screening Program - Implementation (COMAR 10.11.04) CMCH is administratively responsible for this program but collaborate with partners that include the Maryland State Department of Education and Department of Environment which have companion regulations.

Family Planning (Family Law Article, SS2-405, Annotated Code of Maryland) -- Requires DHMH to provide a family planning brochure which is distributed to all marriage license applicants by county clerks. CMCH's Family Planning Program is responsible for providing the family planning information required by this statute.

Perinatal Systems Standards -- the standards are "voluntary" but have been incorporated in the following regulations: COMAR 10.24.12 (State Health Plan for Facilities and Services: Acute Hospital Inpatient Obstetric Services); COMAR 10.24.18 (State Health Plan for Facilities and Services: Specialized Health Care Services -- Neonatal Intensive Care Services); COMAR 30.08.01 (MIEMSS -- Designation of Trauma and Specialty Referral Centers -- General Provisions)

Identification of Infants (Health-General Article, SSSS20-401 and 20-402, Annotated Code of Maryland) -- Specifies the types of procedures to identify a newborn infant to be used by all institutions or related facilities that deliver an infant from its mother, and specifies the information that must be included in each identification procedure and requirements for verification that the identification procedure was performed.

Family Planning Counseling and Services Referrals (Human Services Article, SS5-309, Annotated Code of Maryland) -- Requires the Department of Human Services to administer a Family Investment Program (FIP) whose purpose is to support family efforts to achieve self-sufficiency through services and financial aid geared to individual family needs. In part, FIP provides referrals to FIP recipients for family planning counseling and services, as appropriate, in a manner that is noncoercive, confidential, and does not violate the recipient's religious beliefs. CMHC's Family Planning Program provides the family planning referral information required by this statute.

Hereditary and Congenital Disorders Program (Health-General Article, SSSS13-101 et seq., Annotated Code of Maryland) -- Establishes an Advisory Council and programs to address hereditary and congenital disorders. Originally passed in 1973, this statute was amended in 2008 to put newborn screening in statute. Newborn screening was previously governed by regulations. The language added in 2008, re-establishes the State Public Health Laboratory as the sole laboratory authorized to perform first tier newborn screening, ending the problems caused by allowing a commercial laboratory to compete with the State Public Health Laboratory.

Newborn Screening (COMAR 10.52.12 Screening for Treatable Disorders in the Newborn Child) -  
- Establishes a voluntary program to offer newborn screening for treatable metabolic disorders. Originally promulgated in 1975, these regulations were modernized to conform to the 2008 establishment of a Statewide system for newborn screening in statute. (see Health-General Article, SS13-111, Annotated Code of Maryland) Informed consent is no longer required for screening. The model is now informed dissent with written documentation of parental refusal. This program is jointly administered by the Laboratories Administration (lab analysis and short-term follow up) and by the OGCSHCN (long-term follow up). **//2013/ This statute was amended in 2011 to mandate the legislative report on Critical Congenital Heart Disease (CCHD) and to require that Maryland follow the recommendation of the Secretary of Health and Human Services with regard to newborn screening for CCHD. //2013//**

Hereditary Diseases (COMAR 10.52.01 General Regulations for Hereditary Diseases) (several programs related to genetic disorders are mandated in regulation rather than statute) -- Establishes quality assurance standards for hereditary and congenital disorders services

procured by the State. These regulations, previously administered by OGCSHCN, are now administered by the Laboratories Administration within DHMH.

Sickle Cell Anemia (Health-General Article, SSSS18-501 et seq., Annotated Code of Maryland) -- Establishes a program for screening newborns for sickle cell anemia, monitoring each affected infant's health and providing prenatal education regarding sickle cell anemia. The program is jointly administered by the Laboratories Administration (lab analysis and short-term follow-up) and by the OGCSHCN (long-term follow up, health monitoring and health education). In 2006 and 2007 this statute was amended to provide for a Statewide Steering Committee to improve services for adults with sickle cell disease.

Screening for Neural Tube Defects in the Fetus (COMAR 10.52.14) -- Establishes screening protocols for neural tube defects in the fetus during the second trimester of pregnancy. This testing is supported for uninsured women receiving services through local health departments by the OGCSHCN in partnership with the University of Maryland School of Medicine, Division of Human Genetics.

Program for Hearing Impaired Infants (Health-General Article, SSSS13-601 et seq., Annotated Code of Maryland) -- Establishes a program for universal hearing screening of newborns and early identification and follow-up of infants at risk for hearing impairment. This program is administered by OGCSHCN. The corresponding regulations are COMAR 10.11.02 (Identification of Infants).

Birth Defects (Health-General Article, SS18-206, Annotated Code of Maryland) -- Requires hospitals to report birth defects to the Secretary. Also requires the Secretary to monitor birth defects trends. Originally passed in 1982, this statute was amended in 2008 to expand its authority to collect data on any significant birth defect, not just a list of "sentinel birth defects and to clearly establish the programs authority to review medical records. This program is administered by OGCHSN in collaboration with Maryland's Environmental Public Health Tracking Program.

Program for Crippled Children (Health-General Article, SS15-125, Annotated Code of Maryland) - - Establishes a program to identify and to provide medical and other services to "children who are crippled or who have conditions related to crippling." Based on this legislation, OGCSHCN administers the Children's Medical Services (CMS) Program, which is the payer of last resort for specialty care for low income uninsured or underinsured CSHCN. The corresponding regulations, COMAR 10.11.03 (Children's Medical Services Program), are much more modern in terminology.

#### Center for Maternal and Child Health (CMCH)

The mission of the Center for Maternal and Child Health (CHMH) is to improve the health and well-being of all women, newborns, children and adolescents in Maryland. CMCH focuses on prevention across the lifespan of women and children and serves as DHMH's primary prevention unit for unintended and adolescent pregnancy; infant mortality, low birth weight, fetal alcohol spectrum disorders, childhood lead poisoning, poor asthma outcomes, and racial disparities in outcomes for women and children. The Center collaborates with other FHA units, DHMH units and other State agencies to address: access to prenatal care, breastfeeding promotion, childhood obesity prevention, cervical and breast cancer screening, access to family planning, screening and treatment of sexually transmitted diseases, immunizations, child abuse and neglect, early childhood mental health, postpartum depression, suicide, substance abuse, children's environmental health, and services to rape victims. A leading strategy is systems building through partnerships with Medicaid; other State agencies; local health departments; academic medical centers; professional organizations (ACOG, AAP), private non-profits (Planned Parenthood of Maryland); federally qualified health centers (FQHCs); and advocacy groups.

CMCH manages a budget of approximately \$27 million drawn from ten different federal grants

federal grants and one State general fund initiative, Babies Born Healthy. Major sources of federal funding include the Title V-MCH Block Grant and the Title X Family Planning Grant. CMCH has a staff of ~35 professionals that include physicians, nurses, social workers, epidemiologists, educators, community outreach specialists, administrators, and administrative support staff. At any given time, there are also as many as four public health interns and two preventive medicine residents.

Many MCH program priorities are cross-cutting and overlap, so there are no true "silos" within CMCH contrary to the visual image provided by the attached organizational chart.

#### Key MCH Program Components - CMCH

**Women's Health/Family Planning:** An important goal within CMCH's mission to improve the health of women of reproductive age by assuring that comprehensive, quality family planning and reproductive health care services are available and accessible to citizens in-need. The program provides contraceptive and reproductive health care to over 70,000 clients each year through a statewide network of over 80 ambulatory sites located in local health departments, outpatient clinics, community health centers, Planned Parenthood affiliates, and private provider offices. Family planning clinics in 3 jurisdictions are piloting an expanded model of care for more comprehensive women's health based largely on MCHB funded "Women Enjoying Life Longer (WELL) Project" in Baltimore County. Adopting a life span approach and developing new comprehensive women's health strategies is an important opportunity for both Title V-MCH and Title X-Family Planning.

**Maternal health:** CMCH works with local health departments, FQHCs, and hospital to assure access to maternal health services, including medical care, risk assessment, prenatal education, case management, smoking cessation counseling, genetic screening, high-risk referral, home visiting, assistance in obtaining hospital-based services, and referral for family planning, and preconception health care. In collaboration with Medicaid, CMCH supports the Toll Free Maternal and Child Health Hotline (1-800-456-8900) that is linked with the federal hotline 1-800-311-BABY.

CMCH is also working with FQHCs that do not currently provide prenatal care and/or primary prevention services for women to increase local health service capacity. Local health department were once the primary prenatal care providers for low-income and uninsured pregnant women. Their role changed to eligibility and enrollment support when the decision was made to put prenatal care into the Medicaid managed care program, HealthChoice. While virtually all pregnant women who are U.S. citizens or legal immigrants have access to prenatal care under Health Choice, approximately 5,000 Maryland births are to undocumented immigrants. This has forced many health departments to return to some level of safety net provider.

**Fetal and infant mortality reviews:** FIMRs have been underway in all 24 jurisdictions since 1998. FIMRs not only provide important insight into opportunities for systems improvement, they have also served as an important mechanism for local and regional communication, coordination and collaboration on other MCH issues.

**PRAMS:** The Pregnancy Risk Assessment Monitoring System (PRAMS), a CDC supported statewide survey that identifies and monitors selected maternal behaviors, has been a major source of enhanced surveillance since it's inception in Maryland in 1999. The Maryland response rate is among the best of PRAMS states.

**Child, adolescent and school health:** In the area of child, adolescent and school health, CMCH's goal is to promote and protect the health of Maryland's 1.5 million children and adolescents, ages 0-21, by assuring that comprehensive, quality preventive and primary services are accessible. Activities and strategies include funding and support for early childhood initiatives including home visiting, early childhood mental health and promotion of access to a medical home; initiatives that increase blood lead testing, particularly in 'at risk' areas; adolescent health initiatives including

teen pregnancy prevention programs; the Maryland Asthma Control Program; and school health programs, including medical consultation and development of guidelines. Title V funds support screening for lead poisoning; and vision and hearing problems in school aged children. CMCH also works to prevent child and adolescent deaths by, for example, providing leadership for a statewide child fatality review process to determine necessary systems changes; promoting asthma surveillance, planning and interventions to prevent deaths, and collaborating with the Mental Hygiene Administration on adolescent suicide prevention.

In 2008, CMCH played a major part in the establishment of an Adolescent Health Colloquium in partnership with the Johns Hopkins Center for Adolescents (CAH). Several CMCH staff were members of this group and contributed to the development of a new publication "The Teen Years Explained -- A Guide to Health Adolescent Development" published by Johns Hopkins with support from the CDC. CMCH has purchased the guide for use with local Interagency Committees on Adolescent Pregnancy. The guide can be downloaded by going to <http://www.jhsph.edu/adolescenthealth>.

Local health departments: Over half of the MCH Block Grant funding goes to support the local public health infrastructure for MCH Maryland's 24 local health departments. All but Baltimore City are considered units under DHMH authority with local health officers jointly appointed by local government and the DHMH Secretary. MCH funding is included in local health department core funds, (allocated by formula) and in categorical grants that include the Improved Pregnancy Outcomes (IPO) Program. IPO funding supports FIMRs, outreach, and enabling services. A larger MCH proportion of funding goes to Baltimore City where infant mortality, teen pregnancy, and childhood lead poisoning remain important issues.

#### Special Initiatives/Accomplishments - Center for Maternal and Child Health

Babies Born Healthy Initiative and GDU: In 2007, the Maryland General Assembly approved funding for the "Babies Born Healthy" (BBH) initiative to reduce the State's high infant mortality rate. The initiative has focused on prevention services and quality improvement, with the belief that improving infant health requires a comprehensive, multifaceted approach that encompasses family, community, and systems factors associated with poor pregnancy outcomes. The initiative has advanced perinatal standards and quality improvement activities in 25 hospitals through a partnership with the Maryland Patient Safety Center. It has also been strengthening provider capacity and expertise for high risk pregnancies via telemedicine consultation in partnership with Maryland's two academic medical institutions. Women's health services have been enhanced in partnership with WIC. The Office of Minority Health and Health Disparities has established community-based coalition building activities and a pilot "perinatal "navigators" program two jurisdictions with Babies Born Health funding. BBH has served as the important base for the Governor O'Malley's Delivery Unit Initiative to reduce infant mortality by 10% by 2012.

The Babies Born Healthy Initiative has also provided start-up funding to the DHMH Vital Statistics Administration to implement the new web-enabled electronic birth certificate (EBC) in January 2009 for enhanced surveillance. The new EBC adopts the revised U.S. Standard Certificate of Live Birth in Maryland which includes numerous new and revised data items that are critical for public health purposes. The new system will improve the timeliness, completeness, and accuracy of vital records data, and will allow for easier electronic matching of files. One limitation, however, is that a large proportion of Maryland births occur out-of-state (primarily in Washington DC) and these will not be reported in the new system.

Perinatal Standards: Maryland has had voluntary perinatal standards in place since 1998. The standards are periodically reviewed and updated as needed or in accord with new AAP/ACOG Guidelines for Perinatal Care. CMCH convenes and leads the Perinatal Clinical Advisory Committee (PCAC). Members include representatives from ACOG, AAP, ACNM, AWHONN, the Maryland Hospital Association, the Maryland Patient Safety Center, MedChi, the Maryland Association of County (and Baltimore City) Health Officers, Medicaid, and the Maryland Institute

for Emergency Medical Systems and Services (MIEMSS). The standards were last revised and reissued in 2008.

The standards have been adopted in regulation by MIEMSS for the designation of "perinatal referral centers" -- hospitals that can receive maternal and neonatal transfers. CMCH funds a position at MIEMSS to support this process. Hospitals requesting designation must file a lengthy application and undergo comprehensive site reviews every 5 years that include outside experts as well as clinical staff from CMCH.

***/2013/ The standards were recently adapted to require birthing hospitals to address non-medically indicated elective deliveries prior to 39 weeks gestation. The new standard will allow the Department to continue to monitor such deliveries through hospital site visits by the MMQR Committee and the MIEMSS. It will also require all hospitals to develop policies to address these non-medically indicated deliveries. //2013//***

Maternal mortality: In March 2010 Amnesty International released a report entitled, "Deadly Delivery: The Maternal Health Care Crisis in the USA," stating that Maryland's maternal mortality ratio (MMR) is 16.5 deaths/100,000 births, ranked 48th among states. This report includes MMR data compiled by the National Women's Law Center, based on CDC's National Center for Health Statistics (NCHS) 1999-2004 data. As noted in the report, maternal mortality surveillance based solely on death certificates result in undercounting of maternal deaths. Maryland Maternal Mortality Reviews utilizes enhanced surveillance methods include reviewing medical examiner records and comparing the death certificates of women of reproductive age with birth certificates to establish whether a woman had given birth within a year of her death. Enhanced surveillance may identify as many as 90 percent more maternal deaths than providers reported on death certificates. CMCH's Medical Director for Women's Health, Dr. Diana Cheng, co-authored a paper with Dr. Isabelle Horon, Director of the DHMH Vital Statistics Administration, "Intimate Partner Homicide Among Pregnant and Postpartum Women" which was published in June 2010 issue of Obstetrics & Gynecology. The article summarized pregnancy-associated homicide perpetrated by current or former intimate partners in Maryland from 1993-2008, and found it to be most prevalent among women who were African American and under 20 years of age. Homicides occurred most often during early pregnancy.

*/2012/ Three new federal ACA programs began in FY 2011 -- the Maternal, Infant and Early Childhood Home Visiting Program (\$1.0 million), the Personal Responsibility and Education Program (\$962, 931), and Abstinence Education (\$486,000). All are formula grants. //2012//*

***/2013/ The MCH Program continued to fully develop and implement the new ACA funded programs this past year. Progress is reported under the National Performance Measure concerned with teen pregnancy prevention and the State Performance Measure concerned with home visiting. //2013***

#### ***Office of Genetics and Children with Special Health Care Needs (OGCSHCN)***

***The mission of the OGCSHCN is to assure a comprehensive, coordinated, /2013/ culturally competent //2013//*** and consumer-friendly system of care that meets the needs of Maryland's children and youth with special health care needs and their families. The vision of OGCSHCN is to become a nationally recognized leader in developing the unique potential of each Maryland child and young person served through its comprehensive, fully integrated and consumer-friendly system of care. The OGCSHCN strategy is to identify CSHCN as early as possible and facilitate their access to all needed services to optimize outcomes for children and families.

Key Program Components - Office for Genetics and Children with Special Health Care Needs

The OGCSHCN has very strong partnerships with the academic tertiary /specialty care centers. The OGCSHCN provides grant funding to the academic tertiary care centers to partially subsidize

both genetic services and specialty care. Maryland CYSHCN primarily access services at the Johns Hopkins Medical Institutions (JHMH) including the Kennedy Krieger Institute (KKI), the University of Maryland Medical Center (UMMC) and Children's National Medical Center (CNMC). Through its Centers of Excellence Systems grant program, the OGCSHCN provides a partial subsidy to these institutions to support specialty care clinics, outreach specialty clinics, complex care management clinics, wrap around and enabling services. The grants fund a resource liaison function at each center, that is, one or more positions dedicated to assisting families to navigate the system. In terms of genetic services, the Maryland Genetics Network grants fund the academic genetics centers to provide genetic services at their institution, consultations to affiliated community institutions and to operate outreach genetics clinics in 7 locations in low population density areas of the state. The genetics grants also fund specialized laboratory services to promote accessibility and to provide biochemical expertise that is not available elsewhere.

Grants to the academic medical centers also provide partial support for specialty clinics, such as the Comprehensive Hemophilia Treatment Center, Pediatric Sickle Cell Treatment Centers, and transition Clinics for youth with sickle cell disease, hemophilia and diabetes.

The OGCSHCN funds the Local Health Departments (LHD) to provide care coordination and case management for CSHCN and respite care, outreach specialty clinics and provider and family education. This funding also allows for periodic needs assessments and, special projects such as the medical home project in Baltimore City. OGCSHCN reestablished regular regional meetings for LHD CSHCN coordinators to foster education and co-planning.

The OGCSHCN funds 2 organizations, the ARC of Montgomery County and PACT (an affiliate of the KKI) in Baltimore County, to provide medical day care for severely involved, medically fragile, technology-dependent children, 6 weeks to 5 years of age.

Several disorder-specific groups receive subsidies to provide peer support, specialty camps, and respite care for children with disorders such as sickle cell disease, PKU, and neurofibromatosis. One grant partially subsidizes pre-school vision screening in Head Start programs through the Rosalie Sauber Pre-School Vision Screening Program of the Maryland Society for Sight.

The main non-state agency partner of the OGCSHCN is the Parent's Place of Maryland (PPMD), the Family Voices chapter for Maryland. Beginning in 1998, the OGCSHCN provided a grant to support PPMD's role in providing the family and community perspectives for policy and planning, to assist in identifying gaps in services for CYSHCN, to compile information on resources in a database and disseminate this information to parents of CYSHCN (the Family to Family Health Education and Information Center), to maintain a network of regional resource parents, to assist parents of CYSHCN to find needed resources on an individual basis and to develop parent leaders in the community. PPMD is the main partner of the OGCSHCN in building the infrastructure for a comprehensive, community based, culturally competent, family centered, user-friendly system of care for CYSHCN.

In 2008 PPMD, in partnership with the OGCSHCN, Johns Hopkins Bloomberg School of Public Health, and the Maryland Chapter, American Academy of Pediatrics, applied for and was awarded a D70 State Implementation Grant for Integrated Community Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN) from HRSA. The major strategy was to form a "Community of Care Consortium" (CoC) to engage diverse partners in shared planning, implementation, and evaluation of strategies to achieve all 6 core outcomes for CYSHCN. Consortium partners include families of CSHCN, representatives from advocacy groups, physicians, other providers, health care facilities, academic institutions, government and professional organizations, public payers, MCOs, policy analysts and state governmental agencies. **//2013/ The D70 funding ended in FY2012 and the activities of the CoC will be supported by OGCSHCN using Title V CSHCN funds moving forward. //2013//**

The CoC has been meeting quarterly for almost 3 **/2013/ 4 //2013//** years and has working committees around core outcomes to evaluate strategies and assist the member organizations of the CoC to implement evidence-based practices to improve systems of care for CSHCN. One project to assist local pediatric practices to standardize and improve developmental screening and referral into their workflow has engaged 30 practices in the Baltimore metro area and hopes to engage more practices statewide through partnerships with managed care and other practice organizations. **/2013/ This project is slated for expansion through Title V CSHCN funds for FY13. The CoC has a workgroup for Adequate Insurance and Financing for FY13. //2013//** The CoC has proven to be the best mechanism to achieve the formidable task of integrating the components of the existing community based services, since all stakeholders are involved. PPMD and the CoC have been intimately involved with the preparation of the MCH Block Grant Application for 3 **/2013/ 4 //2013//** years and with the 2010 Needs Assessment. PPMD was represented at the MCH Block Grant review for the past two **/2013/ three //2013//** years.

#### Special Initiatives/Accomplishments - Office for Genetics and Children with Special Health Care Needs

In 2010, OGCSHCN underwent an administrative and structural realignment to better meet the needs of Maryland's CYSHCN population as identified through the 2010 Needs Assessment. The OGCSHCN was re-engineered to increase effectiveness and efficiency, and strategies were developed to create a focus on collaboration and teamwork both internally and with external partners. As a result, chronic staffing vacancies have been filled, new positions have been created, and new programmatic priorities have been determined and disseminated. Now that the office is fully staffed, OGCSHCN was also able to reestablish a leadership role in the CoC and the Maryland Statewide Services for Adults with Sickle Cell Disease Steering Committee. As part of this structural realignment, OGCSHCN worked with internal and external stakeholders, including families and grantees, to review the MCH Funding and Services pyramid and evaluate how it categorizes its programs, services, grants, and other activities by pyramid level. This resulted in a large shift in categorizations between what constitutes infrastructure building and direct services. This redefinition also helped to drive the direction of strategic planning, including budgets, for FY13 (the first year significant programmatic and budgeting changes can be implemented.)

In accordance with the state's "Data Systems and Sharing" priority and with office needs, OGCSHCN evaluated its data systems and formulated an office-wide plan to organize and streamline the various data sets and points collected by its programs and initiatives. Accomplishments to date include the integration of the Infant Hearing Program and Birth Defects Reporting and Information System (BDRIS) databases; planned enhancement and expansion of this database; collaboration with outside partners including the Maryland Center of Excellence for Developmental Disabilities to design a reporting system and database for OGCSHCN grantees and LHDs; and the ongoing development of OGCSHCN's Children's Resource map and database (tracking provider and family resources for health care and related services for Maryland CYSHCN.) These data developments have allowed OGCSHCN to build partnerships that lend expertise and personnel that make it possible to apply for external sources of funding to promote OGCSHCN's mission. **/2013/ OGCSHCN continues to make progress in improving data systems: the resource database is close to completion, the Sickle Cell Disease program database has been enhanced, and community resource mapping activities continue. OGCSHCN has plans to completely overhaul its website to improve content and user and family-friendliness. //2013//**

BDRIS, administered by OGCSHCN, is now in compliance with state legislation to provide information and resources to families of children born with birth defects in Maryland. The CoC reviewed a sample letter and documents that are sent to parents and families to this program, and provided significant input to the redevelopment of those documents, making them more family-friendly and culturally competent. A newly established working relationship with Maryland's Vital Statistics Administration will allow for increased rates of identification and follow-up for



BDRIS (as well as the Infant Hearing Program-IHP), and a new provider manual for the BDRIS program has been developed as well as a Care Notebook to distribute as a resource for families to manage their child's care. Parents have reviewed the care notebook materials and their suggestions for updates and changes are being incorporated. The BDRIS program now has a diverse working advisory committee that includes families of CYSHCN.

OGCSHCN has reached a working agreement with the Maryland State Department of Education (MSDE) to share outcome data from MSDE's Infants and Toddlers Program on infants and young children identified through OGCSHCN's Infant Hearing Follow-up Program. This will increase the capability of IHP to evaluate program outcomes and ensure that children with or at risk for hearing loss are receiving necessary services and care.

OGCSHCN, in partnership with The Parents' Place of Maryland (PPMD) completed preparations for a Family and Youth Advisory Council for Maryland's Title V CSHCN program, administered through OGCSHCN. OGCSHCN is now ready to recruit members and hold the first quarterly meeting of the Council./2013/ Upon consulting with national experts on family and youth advisory councils, OGCSHCN has decided to increase family involvement in existing advisory councils and to use existing outside youth groups and councils in the state to inform strategic planning and programs in OGCSHCN. PPMD would like to see a set of guiding principles developed for OGCSHCN that guides the involvement of families in existing OGCSHCN advisory councils./2013

Several OGCSHCN programs have been streamlined to reflect the newly identified state Title V priorities and OGCSHCN needs. All of the programs providing follow-up for infants have been reorganized to follow a model where children are identified through screening, followed until a diagnosis is made, and then referred for ongoing medical care, early intervention and needed support services (this includes the Infant Hearing, BDRIS, Sickle Cell Disease, and Newborn Screening Long Term Follow-up Programs.) The grants review process for OGCSHCN was also redesigned to be aligned with federal and state Title V program priorities and guidelines. OGCSHCN also reassigned a staff position as a Youth Transition Coordinator in order to address the state and federal Title V youth transition priority, and developed a parent survey around youth transition issues that will be administered each year for the next five years.

/2013/ OGCSHCN, in partnership with The Parents' Place of Maryland (PPMD) was awarded a planning grant from HRSA to develop a statewide plan to improve the system of health care and related services for CYSHCN with autism (ASD) and other developmental disabilities (DD). In support of this, OGCSHCN conducted a comprehensive statewide needs assessment of Maryland CYSHCN with ASD and DD, conducted regional strategic planning meetings across the state, and formed a leadership team to guide grant activities. The resulting recommendations from these meetings will be incorporated into the statewide plan, which will be shared and revised at another series of regional meetings during the upcoming year.

In July 2012 the Newborn Bloodspot Screening Follow-Up Program will return to OGCSHCN. The program will be under the supervision of the OGCSHCN Medical Director. In September 2012, the statewide Newborn Screening for Critical Congenital Heart Disease (CCHD) program will be initiated; surveillance and follow-up activities will be carried out by OGCHSCN. In conjunction with Sojourner Douglass College, OGCSHCN is planning a statewide Sickle Cell Awareness and Community Health event in September 2012.

OGCSHCN developed and distributed My Health Care Notebooks and flash drives to families of CYSHCN in Maryland. The notebooks are tools to organize information about CYSHCN's health care and the flash drives contain an electronic version of the Notebook as well as health care transition resources for parents, youth, and providers. These have proven to be very popular among families and service providers. Other agencies in the state have linked the Notebook to their websites. Additionally, OGCSHCN has begun publication of a quarterly newsletter and is distributing it electronically to families, agencies, providers, and others. The newsletter has been

very warmly received.

During 2012, OGCSHCN in partnership with PPMD, started several new initiatives. Three healthcare transition conferences were held across the state to train parents and youth with SHCN about the importance of planning for the move from the pediatric to adult health care systems. A new program, "Parent Connections" was implemented for parents of infants newly identified with hearing impairment

### **C. Organizational Structure**

The Department of Health and Mental Hygiene (DHMH) is one of six State agencies that comprise Governor Martin O'Malley's Children's Cabinet. The other agencies are the Department of Human Resources (DHR), the Maryland Department of Education (MSDE), the Department of Juvenile Services (DJS), the Department of Disabilities (DOD) and the Department of Budget and Management. The Children's Cabinet is coordinated by the Governor's Office for Children (GOC). The GOC Executive Director, Rosemary King Johnston, chairs the Children's Cabinet. DHMH is the designated agency responsible for administering Title V Maternal and Child Health Block Grant funds.

DHMH Secretary John M. Colmers, the former director of the Maryland Health Care Commission, was appointed by Governor O'Malley in 2007. Secretary Colmer's priorities include expanding health insurance coverage, improving the quality of health care services and controlling health care cost growth. In October 2008, Secretary Colmers named Frances B. Phillips, RN, MHA as DHMH Deputy Secretary for Public Health Services. Ms. Phillips oversees the Family Health Administration, the new Infectious Disease and Environmental Health Administration (formerly the Community Health and AIDS Administrations), the State Laboratory, the Office of Preparedness and Response, and the Office of the Chief Medical Examiner. At the same time, a new DHMH Deputy Secretary for Behavioral Health and Disabilities was established; Renata J. Henry was named as first Deputy Secretary to hold this post. Behavioral Health includes the Alcohol and Drug Abuse Administration, the Mental Hygiene Administration, and the Developmental Disabilities.

/2012/ Governor O'Malley was recently elected to his second term. John Colmers resigned as Health Secretary in January 2011 and replaced by Dr. Joshua Sharfstein. Dr. Sharfstein is the former Health Commissioner for Baltimore City and formerly served as a Deputy Director of the Food and Drug Administration under the Obama Administration. //2012//

The Title V Program is within the Family Health Administration (FHA) under the direction of Russell W. Moy, MD, MPH. Dr. Moy reports directly to the Deputy Secretary for Public Health Services, Ms. Frances Phillips. With the retirement of long-time Deputy FHA Director, Joan Salim, on June 30, 2010, FHA has been reorganized with two Deputy Directors. The Deputy Director for Family Health Services is David S. Long. Mr. Long now oversees the Center for Maternal and Child Health, the Office for Genetics and Children with Special Health Care Needs, and the Office of the Maryland Women, Infants and Children (WIC) Program. He is also responsible for oversight of two chronic disease hospitals and legislation/regulations, and information technology within FHA. Donna Gugel is Deputy Director for Prevention and Disease Control which includes the Center for Cancer Surveillance and Control, the Center for Health Promotion, Education and Tobacco Control, and the Office of Chronic Disease Prevention. She also has responsibility for financial management, health policy and planning, and office systems and support services. The State Dental Director, Dr. Harry Goodman, heads the Office of Oral Health and reports directly to Dr. Moy.

***/2013/ During this past year, there were several changes in leadership within FHA. Dr. Russell Moy resigned as the Director of the Family Health Administration to become the Deputy Health Officer for the Harford County Health Department. Ms. Donna Gugel, one of two Deputy Directors, under Dr. Moy's leadership became the Acting Director of FHA. Mr.***

***David Long, the other Deputy Director, resigned in February 2012 and was replaced by Ms. Kelly Sage as the Acting Deputy Director. //2013//***

FHA oversees a diverse array of public health programs within eight offices and two chronic rehabilitative facilities. The target population includes Maryland's total population of 5.6 million people, covering the lifespan from pregnancy to adulthood. Within the total population, at risk and vulnerable populations including low income, uninsured and medically underserved populations are programmatically identified and safety net services are provided.

***/2013/ Effective July 1, 2012, DHMH Deputy Secretary Phillips, reorganized the administrations and units within her Deputy Secretariat with the goal of strengthening the State's capacity to focus on a range of related public health within the context of the "four pillars of public health." Under the reorganization, the Family Health Administration and the Infectious Disease and Environmental Health Administration (IDEHA) have been consolidated into a new Prevention and Health Promotion Administration (PHPA). Ms. Heather Hauck (former director of IDEHA) is directing the new administration in an acting capacity and Donna Gugel (former Acting FHA Director) will serve as the Deputy Director.***

***There are four Bureaus within PHPA:***

- . Maternal and Child Health Bureau, Acting Director, Bonnie Birkel***
- . Environmental Health Bureau, Director, Cliff Mitchell***
- . Cancer and Chronic Disease Bureau, Acting Director, Kelly Sage***
- . Infectious Disease Bureau, Director, Deborah McGruder***

***In addition, a new Administration, the Health Systems and Infrastructure Administration (HSIA) was created. Dr. Diane Dwyer is the acting Director. The HSIA will focus on initiatives such as the State Health Improvement Plan, working with Federally Qualified Health Centers, improving School Health, and Workforce Development.***

***The reorganization affects programs administered with Title V Block Grant funds. For the first time, that the State will have a Maternal and Child Health Bureau (MCHB) that includes programs administered with Title V, Title X and federal WIC funds. Bonnie S. Birkel (former Director of the Center for Maternal and Child Health) is the Acting Director of the new Maternal and Child Health Bureau. As the attached chart shows, the MCH Bureau includes four offices: the Office of Family Planning and Home Visiting (Bonnie Birkel, Director), the Office of Surveillance and Quality Initiatives (Dr. Lee Woods, Director), the Office of Genetics and People with Special Health Care Needs (Donna Harris, Director) and the Office of Maryland Women, Infants and Children (WIC) Program.***

***The staff and functions of the former Center for Maternal and Child Health (CMCH) are now divided between the Office of Family Planning and Home Visiting and the Office of Surveillance and Quality Initiatives. In addition, several former CMCH programs were transferred to other bureaus or administrations. Environmental health related programs (childhood asthma and childhood lead poisoning prevention programs) formerly under the umbrella of CMCH were transferred to the Environmental Health Bureau. A new Office of School health has been established under the new Health Systems and Infrastructure Administration and MCH staff and funding have been transferred to that unit. The functions and staff of both the former Office for Genetics and Children with Special Health Care Needs, and the Office of the WIC Program remain the same.***

***Current organization charts for DHMH, PHPA and MCHB are attached. //2013//***

More details are the reorganization will be provided at the Title V grant review meeting in August 2012.

***An attachment is included in this section. IIIC - Organizational Structure***

## **D. Other MCH Capacity**

Maryland's MCH Program includes a highly skilled and diverse team of public health professionals representing a variety of disciplines. This team plans, manages, and monitors Title V activities for Maryland from the downtown Baltimore offices of Maryland's State Office complex. In addition, MCH staff in local health departments, including a cadre of community health nurses, physicians, program administrators and clerical personnel, are also supported by Title V funds.

Center for Maternal and Child Health (CMCH)

***//2013/ As described in the Organizational Structure section, the DHMH Deputy Secretary for Public Health Services (PHS) undertook a major reorganization, effective July 1, 2012. A new Bureau of Maternal and Child Health (MCH) has been established. Bonnie S. Birkel is serving as the Acting Director for the MCH Bureau; recruitment for the Director is underway. The Bureau of MCH includes four offices: the Office of Family Planning and Home Visiting (Bonnie Birkel, Director), the Office of Surveillance and Quality Initiatives (Dr. Lee Woods, Director), the Office of Genetics and People with Special Health Care Needs (Donna Harris, Director) and the Office of Maryland Women, Infants and Children (WIC) Program.***

***The staff and functions of the former Center for Maternal and Child Health are now divided between the Office of Family Planning and Home Visiting and the Office of Surveillance and Quality Initiatives. In addition, several former CMCH programs were transferred to other bureaus or administrations. Environmental health related programs (childhood asthma and childhood lead poisoning prevention programs) formerly under the umbrella of CMCH were transferred to the Environmental Health Bureau. A new Office of School health has been established under the new Health Systems and Infrastructure Administration and MCH staff and funding have been transferred to that unit. The functions and staff of both the former Office for Genetics and Children with Special Health Care Needs, and the Office of the WIC Program remain the same.***

***The Office of Family Planning and Home Visiting includes key programs that address reproductive health and family planning; early childhood health and home visiting; and adolescent health and teen pregnancy prevention. A life course approach to program planning and implementation will serve as the organizing framework for this Office. There are 16 staff members.***

***The Office of Surveillance and Quality Initiatives will focus on MCH surveillance activities, data analysis, and related data-driven quality improvement activities. The staff of nine in this office includes two epidemiologists, a data manager, a database specialist, the PRAMS program administrator as well as two physicians, a nurse-consultant, and a coordinator of special programs. //2013//***

CMCH currently has 35 full and part-time staff providing 34.6 FTEs. As noted on the attached organizational chart, CMCH is organized into four units. The largest of these, Perinatal and Reproductive Health, has 10 FTEs at the central office and 3 FTEs assigned in the field with direct clinical duties. The majority of the positions in this unit are federally funded by Title X. Maryland's commitment to workforce development is evidenced by the number of graduate student internships. Several CMCH staff have faculty appointments or serve as instructors in MPH programs at Johns Hopkins and University of Maryland.

CMCH is directed by Bonnie S. Birkel, CRNP, MPH. Ms. Birkel is a trained nurse practitioner with a Master of Public Health degree and over 25 years of experience in public health. She is responsible for MCH policy development and is the official spokesperson for all MCH and family planning related areas. She has served as CMCH's Director since its inception in 2000.

/2012/ Maura Dwyer, DrPH, was hired as the CMCH health policy analyst in 2011. Dr. Dwyer works closely with Ms. Birkel on the Governor's Delivery Unit Initiative to reduce infant mortality. //2012//

Dr. S. Lee Woods, a neonatologist with a Ph.D. in genetics, serves as Medical Director for CMCH. Dr. Woods oversees and provides medical consultation on clinical policy, quality improvement, and legislative issues. Dr. Woods serves as CMCH's primary liaison with the DHMH Office of Communication for public affairs, and also was recently appointed as Secretary Colmer's designee as Chair of the Morbidity, Mortality and Quality Review Committee.

Dr. Woods is supported by Cheryl DePinto, MD, MPH, Medical Director for Child, Adolescent and School Health, who is board certified in pediatrics and adolescent medicine and serves as Principal Investigator (PI) for the CDC Asthma cooperative agreement; Diana Cheng, MD, Medical Director for Women's Health who is a board certified obstetrician/gynecologist, and serves as the PI for the CDC PRAMS cooperative agreement; and Pamela S. Putman, RN, BSN, MPH who is the senior MCH Nurse-Consultant and serves as Chief of MCH Systems Improvement which includes oversight of the statewide Improved Pregnancy Outcome Program.

Yvette McEachern, M.A., serves as Director of Federal/State MCH Partnerships. Ms. McEachern serves as the Title V Administrator and SSDI Project Director in Maryland and oversees development of the Title V application including data collection, performance monitoring and needs assessment. Ms. McEachern has over 20 years experience as a health policy analyst, research statistician, and program administrator. Key staff in Ms. McEachern's unit include Mary LaCasse, Early Childhood Program Manager and Prevention Coordinator; Christine Evans, the Title V-designated Adolescent Health Coordinator and Teen Pregnancy Prevention Coordinator; Rachel Hess-Mutinda, the Asthma Program Administrator, and Linda Nwachukwu, Asthma Epidemiologist.

/2012/ Ms. McEachern was selected as a 2011-2012 MCH Public Health Institute Fellow. Her personal development project will focus on implementing the life course model in MCH programs. //2012//

/2012/ In 2011, three new Affordable Care Act federally funded programs were added to this unit - Abstinence Education, Personal Responsibility and Education Program (PREP) and the Maternal, Infant and Early Childhood Home Visiting Program. Christine Evans serves as the Abstinence Education Coordinator and administrators to coordinate the PREP and Home Visiting Programs are currently being recruited. //2012//

**/2013/ Ms. Patricia Jones was hired as the State PREP Coordinator. Ms. Mary LaCasse was selected to oversee both the MIECHV Home Visiting Grant and the ECCS Grant. //2013//**

//2012// Dr. Dwyer was appointed the SSDI Project Director in 2011 with support provided by Joan Salim as the SSDI health policy analyst. Andrea Bankoski replaced Linda Nwachukwu as the asthma epidemiologist. //2012//

Marsha Smith, MD, MPH, Director of Perinatal and Reproductive Health, oversees the federal Title X Family Planning Program, the Title X HIV Integration Project, and the Babies Born Healthy Initiative. She has responsibility for oversight of clinical services under the family planning program and supervises a staff of 12. Dr. Smith has been appointed as Secretary Colmer's designee to the State Child Fatality Review Team and oversees the Maternal Mortality Review Program. Dr. Smith is a board-certified pediatrician with previous public health experience as the Medical Director for the Baltimore City Health Department's STD program, and as Acting Assistant Health Commissioner in Baltimore. **/2013/ Dr. Smith resigned her position and oversight for family planning and Babies Born Healthy activities is now handled by Ilise Marrazzo. //2013//**

Lee Hurt, MS, MPH has served as the MCH Epidemiologist since 2007. She is a doctoral student at the George Washington University School of Public Health. Ms. Hurt is the CMCH's primary liaison for data with the Medicaid program, with other units within the Family Health Administration, other DHMH Administrations (including the Vital Statistics Administration), and Children's Cabinet agencies. Ms. Hurt also oversees the PRAMS program.

#### Office for Genetics and Children with Special Health Care Needs (OGCSHCN)

Following several years of chronic under-staffing, OGCSHCN is now operating at full staff capacity with 23 staff members, 22 of whom are centrally located. Key leadership positions within the office have been filled, and new staff positions were created and filled that are reflective of newly identified priorities.

OGCSHCN welcomes Donna X. Harris, BS to her new position as Office Director. Ms. Harris has been with the OGCSHCN as Deputy Director since 1999, was the Acting Director of OGCSHCN following the retirement of the previous director earlier this year, and has over 16 years of experience in public health. Ms. Harris' training is in Special Education and she has hands-on experience working with children with learning disabilities, and working with community organizations in health promotion activities.

Additionally, the OGCSHCN welcomes Deborah Badawi, M.D. as the new Medical Director. Dr. Badawi is a developmental pediatrician with 19 years of experience. She has been specifically serving CYSHCN for 15 years. Her current responsibilities include program management and development for various initiatives, interfacing with state and local medical professionals and associations, legislative and clinical guidance, and grants management and support. Immediately prior to her work with OGCSHCN, she was the Medical Director of the Maryland School for the Blind for eight years.

Meredith J. Pyle, BA is the Health Policy Analyst and Title V CSHCN Specialist for OGCSHCN. She has over seven years' prior experience working with young CSHCN and their families and previously worked with OGCSHCN as a graduate research assistant for almost four years. She is pursuing a doctoral degree in public policy. Ms. Pyle's current responsibilities include a variety of analytic, administrative, and coordinative tasks in support of statewide public health policy development and strategic planning, as well as developing program implementation and program evaluation strategies that align with federal MCHB/Title V guidelines and state regulations and mandates. Ms. Pyle was the project manager for the CYSHCN 2010 statewide Title V Needs Assessment.

OGCSHCN welcomes Tanya D. Green, M.S., CCC-A. Ms. Green is the Director of the Maryland Infant Hearing Program (IHP) with and brings over seventeen years of experience as an educational and clinical audiologist to her position. Her career path, which includes hospital, university, public school, and private practice experience, has always included an emphasis in the hearing, communicative, and educational needs of children. Ms. Green's current responsibilities include overseeing MD IHP, procuring program funding, and building strategic partnerships with MD EHDI stakeholders. Erin D. Filippone, M.Ed., CCC-A, has served as a senior audiologist with the Infant Hearing Screening Program for 5 years and served as acting chief during the recent recruitment for a new director. She has extensive previous experience as the audiologist in a pediatric ENT practice.

OGCSHCN welcomes Debra Harper-Hill, R.N. as the new Program Chief for the Birth Defects Reporting and Information System, Metabolic Nutrition and Sickle Cell programs. Debra comes to the Office with over 20 years of experience in healthcare management in various communities, with an emphasis in managed care. Mrs. Harper-Hill has specific experience program components such as budgeting, cost control, operations, and staffing. She is also the parent of a child with special health care needs.

Patricia Williamson, BSN, RN has served as the chief of the Children's Medical Services program for 7 years. She oversees medical eligibility for the program and reviews and preauthorized all services provided through CMS. Her previous experience with the medical assistance program has been very valuable in assisting eligible families to apply for medical assistance or other programs that may provide broader coverage than CMS.

Stephanie Hood, BA has served as a follow up coordinator for the IHP for 4 years and brings experience in case management. This year, Ms. Hood assumed the role of Youth Transition Coordinator for OGCSHCN and currently splits her time between both positions. Ms. Hood has several years experience working with at-risk children and youth and their families, providing health education, workforce development, and other support services. OGCSHCN is in the process of hiring an additional follow up coordinator for IHP and at that time, Ms. Hood will devote her attention to the Youth Transition Coordinator position full-time. ***/2013/ Ms. Hood left her position with OGCSHCN in 2012. Ms. Antoinette Coward has been hired to fill this position and has many years' experience with project management and health education. //2013//***

Javier Figueroa-Ray, BA, MA, has served for 4 years as the bilingual (Spanish/English) Outreach Coordinator for Montgomery and Prince George's Counties, assisting eligible families to apply for CMS and assisting with the case management for Spanish speaking families. His background in social work and community organization is extremely valuable to the program. He also assists eligible families to apply for primary care through the Primary Care Coalition. ***/2013/ Mr. Figueroa-Ray left his position with OGCSHCN in 2011. Ms. Surayma Roberts has been hired to fill this position and is a bilingual case manager. //2013//***

OGCSHCN has plans to fill a newly created CSHCN Resource Coordinator position with a parent or parents of children with special health care needs. ***/2013/ Ms. Angela Sittler, B.S. and trained emergency medical technician, has been hired in this position. She is a parent of two children with special health care needs and brings passion and innovation to the position.***

***Ms. Lynn Midgette has been hired as OGCSHCN's Grants Administrator. Ms. Midgette has a Master's of Public Health and brings experience and expertise with project management and process improvement. She has been accepted into the MCH Public Health Leadership Institute and is also the parent of a child with special health care needs.***

***Ms. Kay Bhide, M.B.A. has been hired as OGCSHCN's Database Manager in 2012 and has greatly expanded program capacity to organize and analyze data.***

***Ms. Brenda Overton, R.N., M.S. has been hired as a newborn screening follow-up nurse with the Newborn Bloodspot Screening program. She has over 20 years experience in pediatric health care as well as a Master's Degree in Health Information Technology. //2013//***

## **E. State Agency Coordination**

Center for Maternal and Child Health

As noted in Section C, the Governor's Office for Children (GOC) is the coordinating unit for the Children's Cabinet. CMCH has been invited to brief the Children's Cabinet on a number of important MCH issues including: FASD, teen pregnancy, infant mortality, and most recently, home visiting. GOC is a partner in the Governor's Infant Mortality Initiative, and has agreed to serve in an advisory and decision-making role for the new federal home visiting program which will be administered by CMCH. CMCH represents DHMH at annual briefings by GOC to the

Maryland General Assembly Joint Committee on Children, Youth and Families. CMCH also works directly with the Children's Cabinet agencies in a number of programmatic areas. CMCH shares responsibility for school health with the Maryland Department of Education, provides consultation and technical assistance on adolescent health and teen pregnancy prevention to the Department of Juvenile Services, and collaborates with the Department of Human Resources on child abuse and neglect, teen pregnancy prevention, outreach for family planning, and early initiation of prenatal care. At the local level, GOC funds Local Management Boards (LMBs) in every jurisdiction. The LMBs are comprised of the local agency counterparts to the Children's Cabinet agencies. The GOC has provided CMCH with the most recent needs assessments completed by LMBs for the MCH Home Visiting Needs Assessment.

/2012/ CMCH is collaborating with the Governor's Office for Children to implement the new home visiting program. An Advisory Group comprised of key State agency staff and other stakeholders has been formed to provide input on program development and implementation. //2012//

CMCH works very closely with the Maryland Department of the Environment (MDE) and the Department of Housing and Community Development (DHCD) on childhood lead poisoning prevention. CMCH represents the Title V program on the Governor's Lead Commission; Medicaid is also represented on the Commission. In FY 2010, CMCH began collaborating with the Maryland Community Health Resources Commission to establish infant mortality reduction as a priority for Commission grants to safety net providers (primarily FQHCs). CMCH provides technical assistance for review of proposals, and has joined in site visits to grantees with Commission staff.

CMCH plays a major leadership and coordination role within the Family Health Administration and partners with the Maryland WIC program (preconception health, family planning outreach, breastfeeding promotion), the Center for Health Promotion (smoking cessation, injury prevention, intimate partner violence), the Office of Chronic Disease Prevention (women's health, childhood obesity), the Center for Cancer Surveillance and Control (cervical cancer screening), and the Office of Oral Health (child health, perinatal health). Within DHMH, intra-agency partners include the behavioral health programs: the Mental Hygiene Administration (early childhood mental health, youth suicide, and perinatal depression) and the Alcohol and Drug Abuse Administration (perinatal substance abuse, Fetal Alcohol Spectrum Disorders), the Vital Statistics Administration (surveillance), the Office of the Chief Medical Examiner (child fatality, maternal mortality) and the newly formed Infectious Disease and Environmental Health Administration (STIs, immunization, asthma, lead poisoning, and the Children's Environmental Health and Protection Advisory Council). CMCH's collaboration with the DHMH Office of Minority Health and Health Disparities (OMHDD) has already been discussed earlier in the narrative. OMHDD is the primary resource for assuring cultural competency among DHMH and local health department staff. CMCH is frequently a training partner with OMHDD and has representation on the OMHDD Maryland Health Professional Education Committee.

CMCH is represented on the Maryland State School Health Council; the School--Based Health Advisory Council; the Partnership for a Safer Maryland (Injury Prevention); the Maryland Immunization Partnership Committee; the State Early Childhood Advisory Council; the Early Childhood Mental Health Steering Committee; the Maryland Developmental Disabilities Council; the Maryland Caregiver Support Coordinating Council; the Early Head Start Policy Council; the Latino Community Health Care Access Coalition; and the Maryland Suicide Prevention Commission. CMCH is also represented on the National Association of FASD State Coordinators.

/2012/ A Personal Responsibility and Education Program Planning Team comprised of representatives from CMCH, and the Sexually Transmitted Infections/HIV Administration are guiding program development and implementation. //2012//

***/2013/ The Maryland Title V Program is now represented on the Office of Primary Care's***



***Workforce Committee. This Committee's goal is to improve access to primary care services for families by ensuring the availability of a competent primary care workforce particularly in underserved areas of the State. //2013//***

***/2013/ This past year, the Title V Program was asked by the DHMH Center for HIV Care Services to join the Ryan White Part D Network. Quarterly meetings are held with the intent of developing partnerships to build the capacity to address challenges unique to women and youth living with HIV/AIDS. The State receives HRSA funding to support the work of the Network. Members include medical and support services providers and representatives of community based groups. //2013//***

***/2013/ Intimate partner violence (IPV) is becoming an increasing concern for the MCH community. The Medical Director for Women's Health represents the DHMH Secretary on the Governor's Office of Crime Control and Prevention's Family Violence Council. The Title V Program will also be represented on the Teen Dating Violence Subcommittee of the Council. The Medical Director for Women's Health will also work with several Domestic Violence organizations in Maryland on Intimate Partner Violence prevention. DHMH now has web site about IPV, [www.dhmh.maryland.gov/IPV](http://www.dhmh.maryland.gov/IPV). It includes a provider guide for IPV assessment to encourage providers to screen women. //2013//***

***/2013/ The Title V Program is a member of the Comprehensiveness and Integration Team (CIT) for Coordinated Chronic Disease (CCD). The team has been meeting since December and thus far has completed an assessment of common risk factors, target populations, partners, and service delivery methods across multiple programs; defined different levels of program coordination; and identified strategies for increasing coordination and efficiency across categorical programs including MCH. The Team is also working to align CCD with the State Health Improvement Process and multiple programs are collaborating to expand worksite wellness initiatives through Healthiest Maryland Businesses. The goal is to develop a State Plan, and funding proposals to move the initiative forward. //2013//***

Office for Genetics and Children with Special Health Care Needs (OGCSHCN)

OGCSHCN has working relationships with the following agencies/offices within DHMH: the Center for Maternal and Child Health, the Laboratories Administration, Environmental Health Protection and Tracking Program, Vital Statistics Administration (VSA), the Developmental Disabilities Administration, the Mental Hygiene Administration, and Medicaid. Other state agencies that OGCSHCN works with include the Department of Disabilities, the Interagency Transition Council, the Maryland State Department of Education (MSDE), 22 of the 24 Local Health Departments in Maryland, and the Maryland Center of Excellence for Developmental Disabilities. In addition to these government entities, OGCSHCN works with numerous community organizations on a regular basis.

Within DHMH, OGCSHCN has had a close collaboration with the Laboratories Administration (Labs) from the early 1960s and the development of newborn screening. The OGCSHCN and the Labs began AFP screening in 1981 serving a largely low income population. With the Medicaid expansions and the resulting decline in uninsured pregnant women, testing volume became too low to justify the State AFP lab and the OGCSHCN provided a partial subsidy to the AFP/Multiple Marker screen lab at University of Maryland Medical Center to serve the remaining patients.

Within FHA, OGCSHCN has collaborated with the Office of Oral Health to educate CYSHCN stakeholders of Oral Health initiatives in the state through a presentation at a quarterly Community of Care Consortium (CoC) meeting. Plans to develop a system of oral health services for CSHCN is a future goal and because great strides have been made in Maryland for children's oral health, it seems possible that a pilot program for CSHCN oral health could be developed in the next several years.

OGCSHCN has expanded its relationship with several departments in MSDE, including the Infants and Toddlers program, the Office of Special Education, and the Office of Student Support Services. OGCSHCN is working with Infants and Toddlers through a data sharing agreement to get outcome data on infants and young children identified through IHP as having a confirmed hearing loss or being at risk for hearing loss. IHP uses an eSP™ database, maintained through OZ Systems, and plans to enhance this database to interface with the BDRIS program, VSA, and MSDE Infants and Toddlers program have been developed and are in the implementation stage. These enhancements will allow OGCSHCN programs the ability to do more timely follow up with families to ensure that infants receive appropriate services as soon as possible. Additionally, OGCSHCN and MSDE have partnered on several initiatives to improve youth transition to adulthood, including adding information on health care transition to MSDE's Family Transition Guide (which is distributed to families of students with IEPs who are 14 years of age or older), and plans to develop health care transition training materials for school nurses and health aides. ***/2013/ OGCSHCN has worked with the Office of Child Care within MSDE on their Race to the Top application and is receiving funding to provide training in developmental screening for primary care clinicians across the state. //2013//***

OGCSHCN partners with the academic tertiary care centers by providing a partial subsidy for their specialty clinics and their genetics clinics. Genetics and pediatric specialty clinics rarely break even and the State grants offset their losses. In return, the centers provide care for CSHCN in their own institutions, within their referral networks and through a series of outreach clinics to bring these specialized services to outlying parts of the State. Local health departments and sometimes local community hospitals host these outreach clinics. OGCSHCN hopes to expand the outreach clinic network to include specialties such as mental health, neurology, and behavioral and developmental health in underserved regions of the state. Primary partners are Johns Hopkins Medical Institutions (JHMI) including the Kennedy-Krieger Institute, the University of Maryland Medical Center (UMMC) and Children's National Medical Center (CNMC).

The OGCSHCN has a very close partnership with Parents' Place of Maryland (PPMD), the Maryland Family Voices chapter. PPMD is a broad umbrella organization advocating for families of CSHCN. Together, PPMD and OGCSHCN lead the CoC. This statewide Consortium includes CYSHCN stakeholders from various public and private entities. Government agencies who participate in the CoC include various offices from DHMH, DDA, Medicaid, the DD Council, DHR, MHA, MSDE, several local health departments, and several local Infants and Toddlers programs.

OGCHCN also has representation on numerous interagency councils, task forces, and committees. These include various committees of the Maryland Chapter of the American Academy of Pediatrics, the Advisory Council for Hereditary and Congenital Disorders, the Advisory Council for Hearing Impaired Infants, the State Interagency Coordinating Council for Infants and Toddlers, the Traumatic Brain Injury Advisory Council, the Maryland Dental Action Coalition, the Interagency Transition Council, the Developmental Disabilities Care Givers Support Coordinating Council, and the Maryland Alliance of PKU Families. ***/2013/ OGCSHCN is actively involved with the Maryland Commission on Autism and is consulting on the final report due to the state legislature. The Maryland Chapter of the AAP has identified an EHDI Chapter Champion to work with Maryland's IHP program. //2013//***

#### Coordination with Medicaid

An updated Title V/Title XIX/Title X/WIC cooperative agreement between the Family Health Administration and Medicaid has been approved. The seventeen page document contains eight sections: administration and policy; reimbursement and contract monitoring; data exchange; outreach and referral activities; training and technical assistance; provider capacity; system coordination; and quality assurance. Each of these sections is further organized into sections for primary preventive services and oral health; pregnant women and infants; children with special health care, and family planning. CMCH also has established a formal MOA with Medicaid for

collaboration and cost-sharing for the Medicaid Prenatal Risk Assessment which is used by prenatal providers statewide. CMCH and Medicaid recently collaborated on a special project with University of Maryland College Park to develop outreach strategies to increase utilization of family planning and early initiation of prenatal care in Prince George's Co. As previously noted, Medicaid is partner in the Governors infant mortality initiative.

## **F. Health Systems Capacity Indicators**

Asthma ED visit rates have been fluctuating in Maryland. Surveillance is the cornerstone of the Maryland Asthma Control Program. Analysis includes asthma prevalence, emergency department visit rates, hospitalization rates, mortality rates, health disparity assessment, asthma-related health behaviors, and asthma-related health care costs of self-management activities. The 2012 Maryland Asthma Burden Report (most recent report available) indicates that statewide, an estimated 216,000 children have been diagnosed with asthma at some point in their lifetime. This represents 16.4% of children. Averaging 2008-2010 data, an estimated 11.9% of children currently had asthma. Children under the age of 5 had the highest hospitalization rate of any age group at 42.0 hospitalizations per 10,000 population in 2010. Hospitalization rates for African Americans in 2010 were 2.7 times higher than that of Whites (30.0 vs. 11.0 per 10,000). The emergency department visit rate was 5.1 times higher for African Americans as compared to White Marylanders (150.0 vs. 29.7 per 10,000).

The State's ability to address asthma from a public health perspective has been influenced by legislation mandating creation of a State Asthma Control Program and CDC funding to support asthma control activities. The Maryland Asthma Control Program (MACP) addresses both pediatric and adult asthma and is administratively housed in CMCH. Maryland has received a CDC asthma grant since 2001 that supports staff salaries (i.e., an asthma epidemiologist, administrator and evaluator) and funds sub-grantees. Title V partially supports the costs of administrative staff, program printing and the purchase of educational materials. A Title V grant to Baltimore supports the City's Childhood Asthma Program.

MACP continues to work with the Maryland Department of Education, local departments of education and local health departments to implement the Asthma Friendly Schools program. Thus far, over 60 schools have been designated as an Asthma Friendly School. In addition, MACP will expand the program to include child care centers and family based programs as designated Asthma Friendly Child Care Centers. In addition, the MSDE is currently developing a Quality Improvement Ratings Scale (QRIS) to provide a framework for Quality Child Care. The MACP is working with MSDE to assure the criteria for AFCC designation will be included in the QRIS. MACP works collaboratively with a variety of stakeholders on the MACP Executive Committee and Maryland Asthma Coalition to ensure the burden of asthma is addressed in all populations and particular focus on disparate populations including children ages 0-4 and the elderly. Research shows that asthma can be effectively managed with medication and quality medical care delivered based on NAEPP guidelines. Reduction in the hospitalization rate is being addressed by provider education, promotion of appropriate medication use, and outreach to disparate populations. Medicaid data on pharmacy claims, provider visits and hospitalization rates will be used to target outreach and education efforts in 2012.

## **IV. Priorities, Performance and Program Activities**

### **A. Background and Overview**

This section describes Maryland's progress on required national and state performance measures and documents accomplishments in 2011, current activities and the State's plan for FY 2013. In many cases, the most current available data is for calendar (CY) or state fiscal year (FY) 2010. Therefore, for many performance measures, we were unable to report on progress for FY 2011. In several instances, the data for the year 2011 will not be available until the fall of 2012 or later. As this data becomes available, it will be incorporated into subsequent applications.

In FY 2011, Maryland's Title V Program served approximately 402,030 pregnant women, infants, children, and women of childbearing age. As this report will show, Maryland was able to meet or surpass many of its target objectives for 33 performance and outcome measures. This year, Maryland found the following improvements:

- . Overall, infant mortality declined to a low of 6.7 per infant deaths per 1,000 live births in 2010.
- . The teen birth rate continued to decline.
- . More pregnant women are receiving prenatal care services within the first trimester of pregnancy and more women are receiving quality prenatal care services as measured by the Kotelchuck Index.
- . More children enrolled in the State's Medicaid Program are receiving dental services.
- . The rate of child deaths due to motor vehicle accidents is declining.

Challenges include:

- . Increasing racial disparities in infant mortality rates with African American babies now dying at three times the rate of White infants.
- . Increasing rates of hospitalizations among children ages 0-4 with asthma.
- . Increasing numbers of Chlamydia cases among teens.

Maryland's MCH Program seeks to improve and enhance the health of all Maryland women, infants, and children including those with special health care needs through funding of Title V and state supported activities and programs. The Program's vision includes a State in which: all pregnancies are planned, all babies are born healthy, all children including those with special needs reach an optimal level of health, and all women and children have access to quality health care services. Title V activities discussed in this document are designed to reflect this vision.

Activities and services are delivered at each level of the MCH pyramid and directed at each of the Title V population groups: pregnant women and infants, children and adolescents, and children with special health care needs. Reducing infant and child mortality and improving health outcomes are program priorities as described in the next section. All activities and programs are linked to these outcome measures.

### **B. State Priorities**

The State's Title V MCH priorities have not changed since submission of the 2010 MCH needs assessment.

Maryland's priority MCH needs for 2011-2015 remain as:

#1. Women's Wellness: Improve the health and wellness of women during the childbearing years (ages 15-44) to ensure that women are healthy at the time of conception.

Women's wellness or the health of women prior to conception was recognized as an important MCH need by respondents to the MCH Stakeholder Survey and during both rankings at the

March Stakeholder meeting. Women's wellness is a broadly focused issue and Title V staff agreed to narrow the focus for purposes of the needs assessment to address reducing unintended pregnancy through provision of family planning services. Maryland is also moving toward enhancing family planning clinical services to include a comprehensive set of women's wellness services not specifically related to or required for contraception or contraceptive management. These include screening and/or services related to chronic disease, nutrition, overweight/obesity, smoking cessation, mental health, substance abuse, domestic violence, preconception planning, or assisting with access to health insurance or primary care. The provision of family planning services also serve as primary prevention strategy for reducing poor birth outcomes. The proposed State Negotiated Performance Measure: Percentage of Maryland mothers with intended pregnancies: 56.6% in 2008 (PRAMS) (also chosen as a priority measure in 2005).

# 2: Healthy Pregnancy, Pregnancy Outcomes and Infants: Promote healthy pregnancies, pregnancy outcomes and infants by reducing risky behaviors (e.g., substance abuse) and improving access to prenatal care.

Reducing infant mortality and related risk factors is a public health priority in Maryland. Significant progress toward reducing infant mortality and improving birth outcomes in Maryland that had been achieved during the 1990's has now stalled, with little improvement made for nearly a decade. Governor O'Malley has identified a 10% reduction in infant mortality in Maryland by 2012 as one of his top policy goals. MCH stakeholders noted that healthy pregnancies and pregnancy outcomes are more likely to occur when mothers are healthy at conception; receive adequate, quality prenatal care; have adequate social and emotional supports; and avoid risky behaviors such as smoking and alcohol and drug use. PRAMS data show that 8% of Maryland women drank in their third trimester of pregnancy. This was viewed as unacceptable by Title V staff and stakeholders and once again, it was decided that additional outreach and education to both women and health care providers is needed. Therefore, the proposed state performance measure remains as: Percentage of women who use alcohol during the last three months of pregnancy (Data source: MD PRAMS Survey)

#3. Healthy Children: Promote early and middle childhood health, healthy child development and parent-child connectedness by increasing access to evidence based home visiting programs

Healthy children require healthy families and/or family support systems, quality early education, safe and nurturing home and learning environments, and access to quality preventive and primary health care. For many Maryland children and families, these requirements have been fully or at least partially met. For others, many challenges exist.

- . An estimated one in ten Maryland children ages 0-18 lived in households with incomes below the poverty level in 2008. More than 8,000 Maryland children lived in foster care homes at some point in 2009.
- . In 2009, there were 31,206 investigations of child abuse and neglect conducted in Maryland. In 20% of the cases (6,312), the findings were substantiated.
- . One in five pregnant women do not receive prenatal care within the first trimester in 2008.
- . According to the 2007 National Survey of Children's Health, 41.4% of Maryland children ages 0-17 do not meet the AAP criteria for having a medical home and 6% do not have a usual place for sick and well care.
- . Approximately 244,000 Maryland children have special health care needs.

Similar to findings from the 2005 needs assessment, Title V heard about the need to support and strengthen families to assure that children remain healthy and thrive. This need for support is cross-cutting and required for all Maryland families, especially socio-economically disadvantaged families. However, the Title V Program also recognizes that families with young children are especially vulnerable and in need of services that enhance their ability to address their health needs, meet their developmental needs, and support school readiness.

Over the next five years, the Title V Program will promote healthy children by improving access to home visiting programs in areas of greatest risk. The availability of new federal funding provides the state with an opportunity to expand access to evidence based home visiting programs. Improving access to these home visiting programs was identified by stakeholders as a priority primary prevention strategy for poor birth and child health outcomes. The proposed State Performance Measure is the Number of children enrolled in evidence based home visiting programs in Maryland (Data Source: Maryland Title V Program Data).

**#4. Access to Health Care for Children:** Improve access to preventive, primary, specialty, mental health and oral health care as well as health insurance coverage for all children including those with asthma and other special health care needs

Both data examined for the 2010 population based assessment and comments made by MCH stakeholders through surveys and key informant interviews continually spoke of the need to improve access to health care -- preventive, primary, specialty, mental health, oral health -- for children and adolescents, particularly those that are low-income and/or uninsured children. Major issues identified include the following the shortages and maldistribution of health manpower, language barriers, transportation, and difficulties, and provider unwillingness to accept Medical Assistance.

These data also continued to reveal unacceptable levels of morbidity and mortality among children in the early and middle childhood periods. Areas of continuing concern included asthma, overweight and obesity, dental caries, and mental health/behavioral problems. This priority was selected to ensure continued focus on improving the health of children in the early and middle years. For example, asthma currently affects approximately 123,000 Maryland children ages 0-17 and is the leading cause of hospitalization for children in the elementary and middle school years as well as leading reason for school absenteeism. Asthma is a controllable disease when properly managed. The use of hospital emergency departments for routine asthma management can be an indicator of poor asthma management. The Maryland Asthma Control Program which is administratively housed in the Center for Maternal and Child Health is implementing a statewide plan to reduce mortality and morbidity from asthma by promoting educational and other to improve asthma management. The use of the hospital emergency department for asthma control will continue to be used as the state performance measure for this priority. Proposed State Negotiated Performance Measure: Rate of emergency department visits for asthma per 10,000 children, ages 0-4: 184 in 2007. This compares unfavorably to the Healthy People 2010 goal of 80.

**# 5. Reduce Childhood Obesity:** Promote needed actions to reduce overweight and obesity among children and adolescents

Childhood overweight/obesity was identified as a priority issue both in the 2005 and 2010 MCH needs assessment. Since the 2005 needs assessment when reducing overweight and obesity across all age groups was identified as a priority, adult and early childhood obesity rates have continued to rise in Maryland. The White House Task Force on Childhood Obesity, in its May 2010 report to President Obama, called the childhood obesity epidemic in America a national health crisis. Nationally, almost one in every three children (31.7%) ages 2-19 is overweight or obese. The 2007 National Survey of Children's Health estimates that more than one in four Maryland children ages 10-17 are overweight or obese.

Rising rates of childhood overweight and obesity were repeatedly identified as a concern in stakeholder surveys and discussions. Because obesity is continuing to increase, is a leading cause of premature death, and remains a significant risk factor for several chronic conditions including type 2 diabetes, heart disease, cancer and asthma, Title V staff strongly believed that this issue should remain a priority focus area. The proposed State Negotiated Performance

Measure: Percent of Maryland Medicaid recipients ages 2-19 years that are obese. (Data Source: Maryland Healthy Kids Obesity Database).

#6: Healthy and Productive Youth and Young Adults -- Transition to Adulthood: Improve supports for the successful transition of all youth to adulthood.

Youth transition to adulthood is one of the six core outcomes identified by the federal Maternal and Child Health Bureau for children and youth with special health care needs (CYSHCN). Both quantitative and qualitative data collected for Maryland's 2010 needs assessment indicate that Maryland is struggling to ensure that all YSHCN receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

***/2013/According to the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), Maryland ranked 40th in the nation on achieving this core outcome (up from a rank of 42nd in the 2005-06 NS-CSHCN); less than 37% of Maryland families of YSHCN ages 12-17 reported that their child received the services necessary to make appropriate transitions to adult life. Maryland scored below the national average on many other of the 2005-06 NS-CSHCN transition indicators but was closer to the national average on those indicators in the 2009-10 NS-CSHCN.//2013//***

Participation in transition planning is an important step for families and YSHCN, and increasing the proportion of parents of YSHCN who report engaging in transition planning from pediatric to adult health care has been identified as a Healthy People 2020 objective. According to the 2008 Maryland Community of Care Consortium for CSHCN 2008 Summit Youth Transition Workgroup, Maryland has multiple activities in the state focused on improving this core outcome, but these attempts seem fractured and do not appear to have a common end goal. The state lacks a clearly defined, comprehensive, coordinated system of care to facilitate success in transitioning YSHCN from pediatric to adult-based health care. The issue is compounded by the problem of youth in this age group accessing their own health insurance. Maryland plans to address these barriers by focusing on training families on the transition process as well as by identifying opportunities for collaboration among agencies and organizations working on youth transition issues in the state. The State Negotiated Performance Measure: The percent of YSHCN families who participate in transition planning for their child: 48% in 2009 (Source: Maryland Parent Survey.)

#7: Strategic Partnerships: Sustain, Strengthen and Maximize Strategic Partnerships through the Community of Care Consortium to address CSHCN core outcomes in Maryland

Supporting the development and implementation of comprehensive, culturally competent, coordinated systems of care for CSHCN has been identified as a critical objective for states by the federal Maternal and Child Health Bureau. State Title V programs have been asked to work with family advocates, providers, and other partners to achieve success on the six core outcomes for CSHCN. In 2008, the Parents' Place of Maryland (PPMD) was awarded a federal "State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs" in partnership with the State's Title V program for CSHCN (the Office for Genetics and Children with Special Health Care Needs, or OGCSHCN), the Maryland Chapter of the American Academy of Pediatrics, and the Women's and Children's Health Policy Center at the Johns Hopkins Bloomberg School of Public Health. Through the grant and partnerships, PPMD developed the Maryland Community of Care Consortium for CSHCN (or CoC). Since its inception in the fall of 2008, the CoC Consortium has created a broad alliance of diverse stakeholders in collaborative efforts to improve systems of care for Maryland CSHCN and their families. They oversee and spread the use of evidence-based and best practice strategies both at the state and local levels, using mini-grants to support implementation. Much of the Consortium's work is aligned with the Healthy People 2020 MICH-31 objective to increase the proportion of CSHCN who receive their care in family-centered, comprehensive, coordinated systems.

At a needs assessment stakeholder meeting in March 2010, key Title V CSHCN staff and parent

advocates, working together as a group, identified ongoing stakeholder partnerships as the primary method through which several core outcomes for CSHCN in Maryland should be addressed. Earlier in the meeting, a broad collection of stakeholders from across Maryland had selected those core outcomes as top priority needs for the CSHCN population in the state, including medical home, that families receive needed services through easy-to-use, community-based systems of care, and adequate health insurance and financing. Stakeholders agreed that the improvement of CYSHCN outcomes requires a system-oriented, partnership-based approach that incorporates infrastructure, population-based services, enabling services, and direct services. Stakeholders also concurred that the role of the Consortium is essential to the health of Maryland's Title V program, as the state's CSHCN program office has suffered unprecedented personnel erosion and remains understaffed to the point where fulfilling Title V obligations to Maryland's CYSHCN is virtually impossible without the support and leadership of the Consortium. **/2013/ The state's CSHCN program office is now fully staffed and develops its work plan around the six core outcomes; partnership building and maintenance is central to the work plan.//2013//** The proposed State Negotiated Performance Measure: Percent of CoC members who report five or more collaborative activities in the previous 12 months; 51.8% in 2008 (Source: Maryland Community of Care Partnership Profile).

#8: Data Systems and Sharing: Improve state and local capacity to collect, analyze, share, translate and disseminate MCH data and evaluate programs

Consistent state level data that indicate the well-being of Maryland's CYSHCN population are crucial to measuring the state's progress on the six core outcomes for this population. However, availability of these data are limited due to agency silo issues and fragmentation among government and non-government agencies and organizations serving the CYSHCN population in Maryland. The data most commonly used to measure Maryland's performance around the six core outcomes are national data from two surveys, the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN). While these surveys provide valuable information every five years and allow state-to-state and state-to-nation comparisons of critical data points and outcomes, they do not provide yearly, statewide, or jurisdiction level data that would help Maryland target resources within the state to improve outcomes for CYSHCN. At a needs assessment stakeholder meeting in March 2010, key Title V CSHCN staff and parent advocates, working together as a group, identified the lack of data sharing among agencies as one of the most significant barriers. The need for data sharing and integration in support of MCH populations is recognized in the Healthy People 2010 developmental objective HP2010 23-2: Increase the proportion of Federal, Tribal, State, and local health agencies that have made information available for internal and external public use in the past year based on health indicators related to Healthy People 2010 objectives. **/2013/ This state priority also supports Healthy People 2020 objectives MICH-31: increase the proportion of CSHCN who receive their care in family-centered, comprehensive, coordinated systems; and DH 2: Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.//2013//** The proposed State Negotiated Performance Measure: % of performance measure benchmarks Maryland has reached toward implementing a Data Sharing plan.

## C. National Performance Measures

**Performance Measure 01:** *The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.*

### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| Annual Objective and | 2007 | 2008 | 2009 | 2010 | 2011 |
|----------------------|------|------|------|------|------|
|----------------------|------|------|------|------|------|



|   |             |   |                                      |   |   |
|---|-------------|---|--------------------------------------|---|---|
| <b>Performance Data</b>   |             |   |                                      |   |   |
| Annual Performance Objective  | 95          | 95  | 99                                   | 100   | 100   |
| Annual Indicator  | 100.0       | 100.0   | 100.0                                | 100.0   | 100.0   |
| Numerator   | 182         | 199   | 199                                  | 159   | 149   |
| Denominator   | 182         | 199   | 199                                  | 159   | 149   |
| Data Source   |             | NBS databases (NSS, NEST, StarLIMS, Pediatrix | NBS data bases (StarLIMS and Sickie) | National Newborn Screening Information System | National Newborn Screening Information System |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |   |                                      |   |   |
| Is the Data Provisional or Final?   |             |   |                                      | Final   | Provisional                                   |
|   | <b>2012</b> | <b>2013</b>                                   | <b>2014</b>                          | <b>2015</b>                                   | <b>2016</b>                                   |
| Annual Performance Objective  | 100         | 100   | 100                                  | 100   | 100   |

#### Notes - 2011

Newborn screening (NBS) data is reported by calendar year, CY2011 to be consistent with the reports to the National Newborn Screening and Genetics Resource Center. The 149 confirmed cases include 45 cases of hemoglobin disorders. There are an additional 33 cases of suspected hemoglobin disorders which have not yet been confirmed. There are also 9 cases awaiting final diagnosis from a genetic center and 2 abnormal CF screens awaiting sweat testing.

#### Notes - 2010

This year's data comes from the National Newborn Screening & Genetics Resource Center's National Newborn Screening Information System. According to Maryland Labs Administration, this data does not reflect suspected cases of hemoglobin disorders, as those take at least one year to diagnose and would not yet be reported by the program. Suspected cases of hemoglobin disorders totaled 70 for CY2010.

Update: Final numbers for CY2010 include 74 hemoglobin disorders and 85 other diagnoses confirmed on bloodspot including metabolic, endocrine, and cystic fibrosis.

#### Notes - 2009

Newborn screening data is reported by calendar year, CY 2009, to be consistent with the reports to the National Newborn Screening and Genetics Resource Center (NNSGRC).

A new performance measure is formulated as control of newborn screening laboratory testing was returned to the State. HB 216 (2008) gave the State Public Health Laboratory the sole authority to perform first tier newborn screening tests for Maryland babies. The bill went into effect 01/01/2009. 2008 data was fragmented -being collected from 4 different databases in 2 different labs. 2009 data was gathered from only 2 databases.

While we would like to maintain our record of treating 100% of confirmed cases, we are aware that a single case lost to follow up would significantly decrease our performance. It seems unrealistic to believe that a case could never be lost to follow up- although we are very tenacious.

#### **a. Last Year's Accomplishments**

Maryland screens for all the disorders recommended by the ACMG, the AAP and the March of Dimes including the secondary targets, except for Severe Combined Immune Deficiency (SCID) which was recently added to the recommendations. Funds to purchase equipment for this DNA testing, which requires new technology, have not been available.

In the 2011 Maryland legislative session, the legislature passed SB 786 Newborn Screening-Critical Congenital Heart Disease . This legislation required an expert panel to be assembled by the Advisory Council on Hereditary and Congenital Disorders to evaluate the feasibility of newborn screening for Critical Congenital Heart Disease (CCHD). A report was due to the legislature in December 2011, and the law also required Maryland to follow the recommendation of Secretary Sebelius with regard to this screening.

OGCSHCN continued to phase out its direct care for metabolic nutrition services and is redirecting patients to appropriate genetic centers (supported by OGCSHCN) for nutritional services. The nutritionist provided .50 FTE during FY2011 for metabolic nutrition care to ensure a smooth transition for patients to the genetic centers.

The NBS program follow up works with each child's primary care provider (PCP) and family to assure they receive needed follow-up and confirmed diagnosis as appropriate. The unit continues to work with the State genetics / tertiary care centers to provide diagnostic evaluations. The unit also works with the metabolic genetics, endocrine, hematology and CF centers to assure ongoing care for confirmed cases. In FY 2011, the OGCSHCN provided long-term follow-up services including case management, nutritional management, counseling, health education, and family support to families with confirmed metabolic disorders and children with sickle cell disease. The genetics centers served over 4,300 children and family members, and provided genetic counseling services to over 4,000 individuals. They also completed over 8,600 laboratory services.

In the BDRIS program, a new program chief was hired and additional administrative OGCSHCN staff was reassigned to the program to assist BDRIS in meeting its legislative mandates. These additional resources have made it possible for the program to meet a state mandate that all parents of children identified with a birth defect receive education and information about services and resources. For the first time in many years, the program is now in compliance with state regulations.

**Table 4a, National Performance Measures Summary Sheet**

| <b>Activities</b>  | <b>Pyramid Level of Service</b> |           |            |           |
|--|---------------------------------|-----------|------------|-----------|
|  | <b>DHC</b>                      | <b>ES</b> | <b>PBS</b> | <b>IB</b> |
| 1. Support newborn screening and follow up services for all the disorders recommended by the March of Dimes, the AAP and the ACMG    | X                               |           | X          | X         |
| 2. Support the BDRIS staff.  |                                 | X         | X          | X         |
| 3. Provide short term follow up assuring that all abnormal or invalid test results are followed to resolution (Labs Administration.) |                                 | X         | X          |           |
| 4. Support the Advisory Council on Hereditary and Congenital Disorders to continue to refine lab testing and follow up               |                                 |           |            | X         |

|  |   |   |   |   |
|--|---|---|---|---|
| protocols.   |   |   |   |   |
| 5. Support the State's designated genetics and hematology centers through grants.  | X | X |   | X |
| 6. Provide a metabolic nutritionist from the OGCSHCN to provide case management and nutritional therapy.   | X | X |   |   |
| 7. Provide follow-up for sickle cell disease patients through the 5th birthday and continue to develop resources for transition and care for them as adults. | X | X |   |   |
| 8. Continue to educate providers and parents.  | X | X | X | X |
| 9.   |   |   |   |   |
| 10.  |   |   |   |   |

#### **b. Current Activities**

In FY11, SCD follow up program underwent revisions to improve efficiency: a nurse was hired to assist with SCD follow up program and Children's Medical Services; a more efficient SCD follow up database has been created. Collaboration with IHP and BDRIS resulted in the automatic generation of letters for families of infants identified with a birth defect. Collaboration with the Maryland Environmental Public Health Tracking Program regarding needed surveillance expertise for BDRIS has begun.

The legislative report on CCHD screening completed in December 2011; expert panel that wrote it has become the Advisory Panel on CCHD Screening in Newborns. Regulations and educational materials have been drafted; appropriate groups have been notified of plans.

Enhancements to the Infant Hearing database have begun with CDC funding; including auto download capabilities between the program, birth hospitals, selected pediatric practices, and the VSA, as well as adding a BDRIS page and a module for collecting data on CCHD screening.

In preparation for OGCSHCN assuming responsibility for follow up of abnormal blood spot screening, a new nurse was hired to work full time in the follow up unit. The Advisory Council for Hereditary and Congenital Disorders has advocated for seeking private funding sources to initiate SCID screening. It is also working with the Laboratories Administration on the possibility of participating in a pilot project for X-linked adrenoleukodystrophy screening.

#### **c. Plan for the Coming Year**

Beginning July 1, 2012, OGCSHCN will assume responsibility for the short-term follow up of abnormal or insufficient blood spot screening results. The duties of the contractual medical director and genetics counselor will be carried out by the OGCSHCN medical director and the new pediatric nurse. The hiring of a second nurse for the blood spot follow up program is in progress. The genetics centers will continue to provide consultation to the medical director as needed.

Newborn screening for CCHD will be mandatory beginning September 1, 2012. The BDRIS nurse has taken the lead in organizing efforts to communicate with hospital nurseries. Webinars are planned for July 26th and 27th, 2012 to provide information regarding CCHD, the screening protocol, and the reporting of data through our electronic database. Screening implementation will be monitored by looking at the number of infants screened and following up on the outcome of infants with abnormal results in order to determine the rate of false positives. The Advisory Panel on CCHD Screening in Newborns is reviewing potential follow up questions to ask a clinician in the nursery regarding the infant's course.

The BDRIS module is expected to be deployed by January 2013. This will allow hospitals to enter data electronically on infants born with a birth defect and will eliminate the need for paper reporting and duplicate recording of demographic data. All live born infants are entered in the Newborn Hearing database, and for those having a birth defect, hospital staff will then be able to

enter additional information regarding birth defects. OGCSHCN will work with CMCH to disseminate an educational brochure, "Pocket Tips" about how to prevent birth defects. The brochure was developed in collaboration with Maryland's Environmental Public Health Tracking.

The Advisory Council on Hereditary and Congenital Disorders is working with OGCSHCN and its stakeholders to develop a list of crucial health benefits for CSHCN. Following a presentation by staff from the Governor's Office of Health Care Reform, the Council is aware of venues for input into decisions being made regarding Essential Health Benefits and the Health Insurance Exchange in Maryland.

### **Form 6, Number and Percentage of Newborns and Others Screened, Cases Confirmed, and Treated**

The newborn screening data reported on Form 6 is provided to assist the reviewer analyze NPM01.

|   |  |       |  |                                    |  |       |
|---|--|-------|--|------------------------------------|--|-------|
| <b>Total Births by Occurrence:</b>                | <b>73783</b>                                 |       |  |                                    |  |       |
| <b>Reporting Year:</b>                            | <b>2011</b>                                  |       |  |                                    |  |       |
| <b>Type of Screening Tests:</b>                   | <b>(A) Receiving at least one Screen (1)</b> |       | <b>(B) No. of Presumptive Positive Screens</b> | <b>(C) No. Confirmed Cases (2)</b> | <b>(D) Needing Treatment that Received Treatment (3)</b> |       |
|   | No.  | %     | No.  | No.                                | No.  | %     |
| Phenylketonuria (Classical)                       | 77299  | 104.8 | 97   | 3                                  | 3  | 100.0 |
| Congenital Hypothyroidism (Classical)             | 77299  | 104.8 | 771  | 35                                 | 35   | 100.0 |
| Galactosemia (Classical)                          | 77299  | 104.8 | 24   | 0                                  | 0  |       |
| Sickle Cell Disease                               | 77299  | 104.8 | 184  | 52                                 | 52   | 100.0 |
| Biotinidase Deficiency                            | 77299  | 104.8 | 44   | 1                                  | 1  | 100.0 |
| Cystic Fibrosis                                   | 77299  | 104.8 | 33   | 11                                 | 11   | 100.0 |
| Homocystinuria                                    | 77299  | 104.8 | 175  | 0                                  | 0  |       |
| Maple Syrup Urine Disease                         | 77299  | 104.8 | 86   | 0                                  | 0  |       |
| Other   | 77299  | 104.8 | 128  | 57                                 | 57   | 100.0 |
| beta-ketothiolase deficiency                      | 77299  | 104.8 | 0  | 0                                  | 0  |       |
| Tyrosinemia Type I                                | 77299  | 104.8 | 136  | 0                                  | 0  |       |
| Very Long-Chain Acyl-CoA Dehydrogenase Deficiency | 77299  | 104.8 | 35   | 0                                  | 0  |       |
| Argininosuccinic Acidemia                         | 77299  | 104.8 | 63   | 0                                  | 0  |       |

|  |       |       |     |    |    |       |
|--|-------|-------|-----|----|----|-------|
| Citrullinemia  | 77299 | 104.8 | 20  | 2  | 2  | 100.0 |
| Isovaleric Acidemia                                      | 77299 | 104.8 | 36  | 1  | 1  | 100.0 |
| Propionic Acidemia                                       | 77299 | 104.8 | 48  | 1  | 1  | 100.0 |
| Carnitine Uptake Defect                                  | 77299 | 104.8 | 80  | 0  | 0  |       |
| 3-Methylcrotonyl-CoA Carboxylase Deficiency              | 77299 | 104.8 | 31  | 3  | 3  | 100.0 |
| Methylmalonic acidemia (Cbl A,B)                         | 77299 | 104.8 | 48  | 0  | 0  |       |
| Multiple Carboxylase Deficiency                          | 77299 | 104.8 | 0   | 0  | 0  |       |
| Trifunctional Protein Deficiency                         | 77299 | 104.8 | 0   | 0  | 0  |       |
| Glutaric Acidemia Type I                                 | 77299 | 104.8 | 33  | 0  | 0  |       |
| Sickle Cell Anemia (SS-Disease)                          | 77299 | 104.8 | 184 | 52 | 52 | 100.0 |
| 21-Hydroxylase Deficient Congenital Adrenal Hyperplasia  | 77299 | 104.8 | 128 | 4  | 4  | 100.0 |
| Medium-Chain Acyl-CoA Dehydrogenase Deficiency           | 77299 | 104.8 | 26  | 4  | 4  | 100.0 |
| Long-Chain L-3-Hydroxy Acyl-CoA Dehydrogenase Deficiency | 77299 | 104.8 | 0   | 0  | 0  |       |
| 3-Hydroxy 3-Methyl Glutaric Aciduria                     | 77299 | 104.8 | 48  | 0  | 0  |       |
| Methylmalonic Acidemia (Mutase Deficiency)               | 77299 | 104.8 | 48  | 0  | 0  |       |
| S-Beta Thalassemia                                       | 77299 | 104.8 | 9   | 1  | 1  | 100.0 |

**Performance Measure 02:** *The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>             | <b>2009</b>             | <b>2010</b>             | <b>2011</b>             |
|---|-------------|-------------------------|-------------------------|-------------------------|-------------------------|
| Annual Performance Objective  | 72          | 55                      | 55.5                    | 56                      | 56.5                    |
| Annual Indicator  | 54.8        | 54.8                    | 54.8                    | 54.8                    | 69.3                    |
| Numerator   |             |                         |                         |                         |                         |
| Denominator   |             |                         |                         |                         |                         |
| Data Source   |             | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | NS-<br>CSHCN<br>2009-10 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                         |                         |                         |                         |
| Is the Data Provisional or Final?   |             |                         |                         | Final                   | Final                   |
|   | <b>2012</b> | <b>2013</b>             | <b>2014</b>             | <b>2015</b>             | <b>2016</b>             |
| Annual Performance Objective  | 69.3        | 69.3                    | 69.3                    | 75                      | 77                      |

#### **Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate this indicator for both the 2001 and the 2005-06 CSHCN survey. However, in 2009-2010 there were wording changes and additions to the questions used to generate this indicator. The data for 2009-2010 are NOT comparable to earlier versions of the survey.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

#### **Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM02 indicator for both the 2001 and the 2005-2006 CSHCN survey.

#### **Notes - 2009**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM02 indicator for both the 2001 and the 2005-2006 CSHCN survey.

#### **a. Last Year's Accomplishments**

According to the 2009-10 National Survey of CSHCN (NS-CSHCN), 69.3% of Maryland families of CYSHCN report they are partners in decision-making and are satisfied with services they receive; very similar to the 70.3% of families nationwide who meet this outcome. Maryland ranks 37th in the nation. Hispanic CYSHCN and those with emotional, behavioral or developmental issues are less likely to meet this outcome; those with a medical home are far more likely to meet this outcome.

OGCSHCN continued its support of The Parents' Place of Maryland (PPMD), a non-profit, family-directed and staffed center serving parents of children with disabilities and SHCN. PPMD is the Maryland Chapter of Family Voices. PPMD and OGCSHCN have ongoing partnerships including

the Family-to-Family Health Education and Information Center, a statewide resource which provides information, support, advocacy, and referrals for families of CYSHCN. In FY11, PPMD parent staff provided individual assistance to 1403 families of CYSHCN and 296 professionals (representing a total of 1540 CYSHCN) through telephone, email, and face-to-face meetings. 41.3% of assistance to families in FY11 was related to partnership building; 80% reported that the information was very or extremely useful in partnering with professionals. PPMD provided training to 1092 families and 702 professionals and sends out a monthly newsletter (ParenTalk) covering both health and education topics; in FY11 PPMD sent out 12 newsletters that each reached at least 3025 individuals.

PPMD fosters relationships with organizations connected with ethnic/racial minority populations and provides materials and trainings in Spanish and uses community contacts for translation in other languages. PPMD is very successful in its minority outreach efforts; 31.9% of families served were minorities and 3 sessions were conducted for Spanish speaking families during FY11.

PPMD continued the Family as Faculty program with UMD School of Medicine and Johns Hopkins School of Public Health, facilitating home visit matches and debriefing for pediatric residents and students with diverse families of CSHCN on a monthly/bi-monthly basis. In FY11, 25 families of CYSHCN hosted 51 students. PPMD conducted a variety of 83 workshops for 1792 parents and professionals to increase partnership and advocacy skills and effectively access health care services for CYSHCN in FY11.

OGCSHCN support enables PPMD to identify and support emerging parent leaders to participate in leadership and policymaking activities through sponsored parent participation in the Health LEADers programs; graduates are linked with various state and local committees, councils, and task forces to provide a family perspective. In FY11 a PPMD survey found that 84.2% participate in advisory committees at the local or state level and 89.5% support other parents and provide resources and information to those parents. PPMD staff members, all of whom are parents of CYSHCN, participated in more than 92 meetings at the state and local levels to ensure families are represented in task forces, councils, and other policymaking bodies.

PPMD staff were instrumental in the writing and review of FY10's Title V MCH Block Grant report and application and PPMD's Executive Director attended the Block Grant review at MCHB. PPMD was in the advisory workgroup that assisted with the reorganization of OGCSHCN in FY11 and continued to aid and advise during the implementation of the recommended changes.

OGCSHCN continued to work with PPMD on their State Implementation Grant for Integrated Community Systems for CYSHCN. The CoC is a working group of diverse stakeholders, including families and professionals that holds quarterly meetings and identifies priorities, including building relationships between families and professionals. In FY11, OGCSHCN was able to increase its staff participation in CoC meetings. The CoC held its January 2010 quarterly meeting in Annapolis in order to raise awareness among state lawmakers of current issues facing CYSHCN and their families. Over 35 parents attended and several lawmakers attended. Parents also visited their state representatives in their offices.

The CNMC Family Navigator Program supported by OGCSHCN provides social support, in the form of peer-to-peer mentoring, for families of CYSHCN. Specifically, support includes the provision of informational and emotional support, as well as assistance with health care/educational advocacy.

**Table 4a, National Performance Measures Summary Sheet**

| Activities | Pyramid Level of Service |    |     |    |
|------------|--------------------------|----|-----|----|
|            | DHC                      | ES | PBS | IB |

|  |  |   |  |   |
|--|--|---|--|---|
| 1. Support The Parents' Place of Maryland to provide families of CYSHCN with a central source of information, education, direct family support and referrals                                     |  | X |  | X |
| 2. Support The Parents' Place of Maryland to provide parent training, information, education and support   |  | X |  | X |
| 3. Support parent input into health policy and program design activities   |  |   |  | X |
| 4. Support employment of family members of CYSHCN through PPMD.  |  | X |  | X |
| 5. Collaborate with partners to collect and disseminate data and information from families of CYSHCN via multiple sources  |  |   |  | X |
| 6. Support The Parents' Place of Maryland to maintain a Family as Faculty Program  |  | X |  | X |
| 7. Work with The Parents' Place of Maryland and other stakeholders to maintain a Community of Care Consortium for CYSHCN in Maryland that promotes and supports family-professional partnerships |  |   |  | X |
| 8. Support Parent Navigator activities for Maryland families at Children's National Medical Center.  |  | X |  | X |
| 9. Include parents in ongoing Title V needs assessment activities  |  |   |  | X |
| 10. Include parents in preparing the Title V Block Grant application   |  |   |  | X |

#### **b. Current Activities**

OGCSHCN reorganized its overall strategic plan around the 6 core outcomes; and identified expanding leadership roles of families and providers of CYSHCN in professional/government organizations as a focus. PPMD/OGCSHCN continue to analyze/disseminate data from the 2010 Maryland Parent Survey; in FY12 6 Unmet Needs data sheets were disseminated. A Family-Professional Partnership Fact Sheet using 2009-10 NS-CSHCN data was developed/disseminated by OGCSHCN. OGCSHCN provides leadership to the CoC which held quarterly meetings in FY11. PPMD assisted in preparing the MCHB Title V Block Grant for FY11/13. OGCSHCN will fund CoC in FY13 as the federal D70 grant expired; this will support the continuance of the above activities and parent involvement in activities. Plans for a Family Advisory Council were modified (after a PPMD provided conference call with a national expert on family advisors) to integrate existing advisory councils with more family participation. PPMD started a Latino Family Support Consortium -- this group met quarterly during FY12 and consists of providers, families, and local and state government reps and is designed to increase awareness and partnerships. This will continue in FY13 under OGCSHCN CoC funding. OGCSHCN hired two parents of CYSHCN. In FY12 OGCSHCN's grantee meeting, "Partnering with Families and Organizations" focused on leveraging partnerships and collaboration to develop and enhance family-centered care and featured guest speaker Diana Denboba.

#### **c. Plan for the Coming Year**

The activities described will continue. PPMD will work closely with OGCSHCN staff to develop and implement action plans to strengthen and sustain partnerships, including parent partnerships. CoC is a racially, ethnically, culturally, linguistically, socioeconomically, and geographically diverse group, including the parents and other family members of CYSHCN which identifies and implements strategies to promote family-professional partnerships and cultural competency in all activities. The Mini-Grant program of CoC requires family participation and strategies for cultural competency in all projects. In FY12, mini-grants supported the start of a consortium on the Eastern Shore and will continue in FY13, as will the Latino Family Support Consortium with additional plans to start a Western Maryland consortium.

Family members are required participants in all activities and receive stipends for their participation and reimbursement for travel/childcare. CoC strives to accommodate special needs



of its members; sign and foreign language interpretation provided if requested. PPMD has staff to provide interpretation and Spanish translation of materials.

OGCSHCN houses Maryland's Infant Hearing Program (IHP) which applied for/ received HRSA funds. One of the major goals is to increase family/parent involvement in all aspects, and objectives include the design and implementation of parent outreach, network, education and training through a sub-grant award to a parent organization(s); and parent participation in the annual national EHDI conference. Parents planned the 2012 Maryland EHDI stakeholder conference and a new parent mentoring program, Parent Connections, is connecting parents of infants newly identified with hearing impairment to more experienced, trained parent mentors for support; this will continue in FY13.

OGCSHCN/PPMD in applied/received a HRSA State Planning Grant to develop a statewide plan for improving the service system for children with autism spectrum disorder and other developmental disabilities. Work began in FY12 and will continue throughout FY13 -- parents are heavily involved in the needs assessment and development of the regional and statewide aspects of the plan through participation with other stakeholders in strategic planning meetings and online feedback mechanisms.

OGCSHCN has instituted a new grants review process for the funds it awards; the process was first used in FY12 for FY13 proposals; an outside review committee includes parents of CYSHCN in Maryland. This process will continue in FY13 for FY14 proposals.

An OGCSHCN CYSHCN parent employee and Maternal and Child Health Public Health Leadership Institute fellow is developing a toolkit, entitled "Families at the Center", for building family-centered care at the organizational level. By reviewing existing tools and resources and identifying deficiencies, the fellow is constructing a practical, action-oriented instrument for fostering family-centered care among grantees.

**Performance Measure 03:** *The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>             | <b>2009</b>             | <b>2010</b>             | <b>2011</b>             |
|---|-------------|-------------------------|-------------------------|-------------------------|-------------------------|
| Annual Performance Objective  | 62          | 46                      | 46.5                    | 47                      | 47.5                    |
| Annual Indicator  | 45.6        | 45.6                    | 45.6                    | 45.6                    | 44.2                    |
| Numerator   |             |                         |                         |                         |                         |
| Denominator   |             |                         |                         |                         |                         |
| Data Source   |             | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | NS-<br>CSHCN<br>2009-10 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                         |                         |                         |                         |
| Is the Data Provisional or Final?   |             |                         |                         | Final                   | Final                   |
|   | <b>2012</b> | <b>2013</b>             | <b>2014</b>             | <b>2015</b>             | <b>2016</b>             |
| Annual Performance Objective  | 44.2        | 44.2                    | 44.2                    | 48                      | 50                      |

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. The data for the 2001 and 2005-2006 surveys are not comparable for NPM 3. However, the same questions were used to generate the NPM 3 indicator for both the 2005-2006 and 2009-2010, therefore these two surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions and additions to the questions used to generate the NPM03 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #03.

**Notes - 2009**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions and additions to the questions used to generate the NPM03 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #03.

**a. Last Year's Accomplishments**

According to the 2009-10 National Survey of CSHCN (NS-CSHCN), 44.2% of Maryland families of CYSHCN report CSHCN receive care in a medical home; similar to the 43% nationwide for this outcome. Maryland ranks 28th in the nation. Hispanic CYSHCN and those without adequate insurance are less likely to meet this outcome; those with adequate insurance are far more likely to meet this outcome.

The Complex Care Program at Children's National Medical Center supports medical homes by bridging/filling the gap between primary care providers and tertiary services. Both clinical and care coordination services are offered. In FY11 112 patients were seen in the clinic, 15 were new to the program, and 106 families received family navigator services. JHU Systems Development supports CSHCN patients at Harriet Lane Clinic with asthma, ADHD, and SCD and has a system to identify and electronically track them. Care managers are assigned to coordinate services and treatment with hospitals and other providers using enhanced communication between HLC providers and specialists. In FY11, over 950 CYSHCN received care at HLC. Pediatric residents at HLC receive multiple trainings on the medical home model, and a web-based medical home training module is utilized by residency programs across the country; in FY11 more than 1800 residents were trained. University of Maryland Complex Care clinic served 39 patients and provided training for residents on medical home provision.

OGCSHCN continued to work with PPMD to provide leadership/staff support to continue the activities of the Maryland Community of Care (CoC) Consortium for CYSHCN. At a quarterly meeting of the CoC in FY11, attendees reviewed strategies developed at the 2008 Summit to advance medical home in Maryland. Next steps and appropriate partners to pursue strategies were identified including realigning provider compensation to support the use of medical home components within practices. The CoC funded a project to the One World Center for Autism in Prince George's County to develop training materials for families and providers around medical home.

PPMD, through their Family as Faculty program and provides students with information on the medical home concept and the need for families of CYSHCN to have a medical home. All UMD combined or categorical pediatric residents participate in this program during their behavioral developmental pediatrics rotation, and Johns Hopkins School of Public Health master's students also participate in this program.

Improving the system of care coordination through local health departments (LHDs) has continued to be an OGCSHCN priority. With OGCSHCN support, in FY11 at least 12 LHDs provided case management services for a total of 958 CSHCN and their families. There were 1020 contacts among LHDs to collaborate with primary care providers, and 961 families received information about medical homes through workshops or outreach from LHDs. 11 LHDs provided respite care in FY11 to 553 CSHCN and their families.

The Baltimore City Health Department (BCHD), with support from OGCSHCN, expanded its "Medical Homes Project" aimed at improving the quality of medical homes for children. This project improves the rates with which pediatric primary care providers in Baltimore City effectively screen young children for developmental delays. An article describing the findings was published in a peer-reviewed journal in FY10. In FY11, this project was chosen by the leadership of the CoC to participate in the NICHQ Learning Collaborative for D70 State Implementation Grantees, and as a result key continuous quality improvement measures were incorporated into project activities. In FY11 3 of the largest federally qualified clinics received targeted public health presentations; 2 of the targeted clinics, Total Health Care and Baltimore Medical System have multiple sites so a substantial number of providers and medical staff received important detailing information (150 providers in thirteen medical sites.) The program has moved into areas surrounding Baltimore City. An effort to include family practitioners (FPs) in addition to pediatricians (approximately half of the practices in JHCP do not have pediatricians so children are seen by FPs) began in FY11 and continued into FY12.

Also in FY11, OGCSHCN sponsored the Maryland EHDI Stakeholder conference, and the keynote speaker topic was medical homes for children impacted by hearing impairments.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Support the Complex Care Program at Children's National Medical Center, the ASK program at University of Maryland  | X                        | X  |     | X  |
| 2. Support efforts to educate families and providers about medical home partnerships through dissemination of materials   |                          | X  |     | X  |
| 3. Fund gap-filling care coordination for CYSHCN through local health departments.  | X                        | X  |     |    |
| 4. Support multiple efforts to improve developmental screening and appropriate referral for all children within the medical home through policy-level and practice-level change                 |                          |    |     | X  |
| 5. Work with The Parents' Place of Maryland and other stakeholders to continue with the Community of Care Consortium for CYSHCN in Maryland that promotes and supports medical home improvement |                          |    |     | X  |
| 6. Support Johns Hopkins University to continue to implement a medical home model for selected high prevalence, high impact and/or high cost conditions within the Harriet Lane Clinic          | X                        | X  |     |    |
| 7. Support The Parents' Place of Maryland to maintain and expand a Families as Faculty Program that incorporates medical home education for medical and public health students                  |                          | X  |     | X  |

|   |  |  |  |   |
|---|--|--|--|---|
| 8. Support MD AAP and the CoC partner in a series of regional medical home forums to bring together physicians, allied health providers, local health departments, community service providers, families. |  |  |  | X |
| 9. Partner with the University of Maryland on Project IMPACT to develop specialty modules to prepare medical home providers to better handle common specialty concerns in their offices                   |  |  |  | X |
| 10. Sponsor the Maryland EHDI conference with a keynote address about medical homes.  |  |  |  | X |

#### **b. Current Activities**

In FY12 OGCSHCN reorganized its overall strategic plan around the 6 core outcomes; and identified increasing access to specialty care as a focus for improving medical home. Subgoals include collaborating with partners statewide to maximize specialty clinics and expanding telehealth and identifying all care coordination and case management services in the state. A Medical Home Fact Sheet based on 2009-10 NS-CSHCN data was developed and disseminated by OGCSHCN. OGCSHCN revised the My Health Care Notebook for families to organize and support health management for their CYSHCN; the notebook is being widely distributed to families directly and through community providers in both paper and flash drive formats and is available on OGCSHCN's and other agencies' websites. The Medical Homes Project continued to operate with the support of the CoC, PPMD, and OGCSHCN. During FY12, the Improving Medical Home Partnerships for Specialty Access through Coordination and Training (IMPACT) program was completed; this project developed specialty modules to prepare medical home providers to better handle common specialty concerns in their offices and a collaborative care agreement was developed for use by practices that participate in the specialty module training.

#### **c. Plan for the Coming Year**

The activities described above will continue with one major change. Funding to the Harriet Lane Clinic for on-site promotion of medical home and care coordination is being redirected to support full-scale implementation of the Baltimore Medical Homes project for multiple regions of the state. Due to the measurable and successful outcomes produced through this project, OGCSHCN asked the project coordinator, Tracy King, to develop a plan to expand the program statewide using a regional approach. She developed a plan and submitted a grant proposal to OGCSHCN and was approved for FY13. Implementation will start in the Eastern Shore region and continue in the Baltimore metropolitan area.

A position has been identified in OGCSHCN that includes a medical homes coordinator function, which would be responsible for implementing medical home leadership activities in the state. This would enable progress on the medical home goal for the CoC and for the state on this national performance measure.

Training of providers using the modules developed through the IMPACT project are planned for FY13 using the University of Maryland's Blackboard site.

OGCSHCN also plans to focus on data gathering and integration as it relates to medical homes in the state. Efforts are underway to identify potential and existing sources of data and to gain access to and integrate that data to better track progress on medical home outcomes in Maryland. A partnership continues between OGCSHCN and the Maryland Center of Excellence for Developmental Disabilities (MCDD) to pursue funding and collaborative activities for data system development.

Also in FY13, OGCSHCN plans to contact families and agencies providing care coordination to develop work groups to develop standards for levels of care coordination required by families.

OGCSHCN partnered with PPMD in applying for a HRSA State Planning Grant to develop a statewide plan for improving the service system for children with autism spectrum disorder and other developmental disabilities. This grant was awarded and work began in FY12 and will continue throughout FY13 -- the needs assessment includes a section on medical home and the framework for the plan is the six core outcomes, including medical home. In FY13, the Center for Maternal and Child Health is partnering with the Maryland Chapter of the AAP and with the Maryland State Department of Education to survey and conduct focus groups with pediatricians about medical homes. Data gathered through these activities will be shared with OGCSHCN and will inform the statewide plan.

**Performance Measure 04:** *The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>             | <b>2009</b>             | <b>2010</b>             | <b>2011</b>             |
|---|-------------|-------------------------|-------------------------|-------------------------|-------------------------|
| Annual Performance Objective  | 70.5        | 65.7                    | 65.9                    | 66.1                    | 66.3                    |
| Annual Indicator  | 65.5        | 65.5                    | 65.5                    | 65.5                    | 61.5                    |
| Numerator   |             |                         |                         |                         |                         |
| Denominator   |             |                         |                         |                         |                         |
| Data Source   |             | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | NS-<br>CSHCN<br>2009-10 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                         |                         |                         |                         |
| Is the Data Provisional or Final?   |             |                         |                         | Final                   | Final                   |
|   | <b>2012</b> | <b>2013</b>             | <b>2014</b>             | <b>2015</b>             | <b>2016</b>             |
| Annual Performance Objective  | 61.5        | 61.5                    | 61.5                    | 67                      | 70                      |

#### Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate the NPM 4 indicator for the 2001, 2005-06, and 2009-2010 CSHCN surveys.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

#### Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM04 indicator for both the 2001 and the 2005-2006 CSHCN survey.

**Notes - 2009**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM04 indicator for both the 2001 and the 2005-2006 CSHCN survey.

**a. Last Year's Accomplishments**

According to the 2009-10 National Survey of CSHCN (NS-CSHCN), 61.5% of Maryland families of CYSHCN report their CSHCN have adequate insurance to cover needed services; very similar to the 60.6% of families nationwide who report meeting this outcome. Maryland ranks 25th in the nation. CSHCN with functional limitations and those with emotional, behavioral or developmental issues are less likely to meet this outcome.

OGCSHCN continued to partner with The Parents' Place of Maryland (PPMD) and its Family-to-Family Health Information and Education Center. A goal of is to increase the knowledge and skills of parents/caregivers of CYSHCN so they may more effectively access health care services for their children. PPMD developed and continuously refines health-related workshops for families, several of which are related to insurance issues including "Show me the Money" and "Financial Hardships for Maryland Families of CYSHCN". Workshops are scheduled on an ongoing basis throughout the state, both face-to-face and by teleconference. In FY11, PPMD staff conducted 83 training events for a total of 1792 parents and professionals. Some of this training included Special Needs Coordinators from Maryland MCOs. PPMD staff members are also available to provide individual assistance to parents of CYSHCN through telephone, email, and face-to-face meetings. In FY11, individual contact was provided to 1403 parents and 296 professionals; 6.1% of assistance requested was for issues related to financing. Among parents needing help around health care financing, some examples of help requested are information on Medicaid and various questions and concerns around private insurance.

OGCSHCN continues its partnership with PPMD in the Maryland Community of Care (CoC) Consortium for CSHCN. In FY11, the CoC was funded through a State Implementation grant awarded to PPMD, and is a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems that holds quarterly meetings and identifies priorities, including adequate health insurance and financing. Maryland Medicaid MCOs Special Needs Coordinators are members. In FY11, CoC saw an increase in the number of MCO Special Needs Coordinators attending quarterly meetings. Several MCOs which had not sent representatives in the past began attending in FY11. During the inaugural summit for the CoC in November 2008, the group identified barriers to adequate insurance and financing in Maryland. These issues were revisited during FY11 and the group identified strategies and action steps to improve this core outcome, including the development of a group for networking, outreach, education, advocacy, and legality around financing and development of a legislative agenda to address policies for financing.

OGCSHCN continued to support two of Maryland's medical daycare centers due to inadequate reimbursement from Medicaid for nursing services. In FY11 these centers served a total of 113 CSHCN.

OGCSHCN provided payment for specialty care and related services through the Children's Medical Services Program (CMS) to CYSHCN who are uninsured or underinsured and have family incomes up to 200% FPL. Recent changes to the program's eligibility guidelines as well as the continued presence of two bilingual staff served to increase the number of eligible children for the program, though one of the bilingual staff left the program in FY10; another bilingual staff was recruited and hired in FY11. The vast majority of the children served by the program are Hispanic immigrants. The program's Spanish-speaking staff, the Bilingual Outreach Coordinator and the Care Coordinator for Montgomery County, worked directly with families and providers to facilitate access to timely and appropriate CMS program services. The capability to directly provide Spanish-language services to CMS families continued to be invaluable to the program, and promoted greater parent-program communication as well as an increased parent

education/awareness of related program services.

The Maryland Chapter American Academy of Pediatrics (MDAAP) continued Assuring Better Child Health and Development Screening Academy through CoC funding. In FY11, MDAAP continued training pediatric providers throughout Maryland on approved screening tools as well as how to seek reimbursement for screenings.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Support The Parents' Place of Maryland to educate parents of CYSHCN about health insurance and how to access services for their children through a series of workshops                               |                          | X  |     | X  |
| 2. Support parent input into policy and program design activities related to health insurance for CYSHCN  |                          |    |     | X  |
| 3. Provide payment for specialty care and related services for CYSHCN who are uninsured or underinsured with family incomes up to 200% FPL through the Children's Medical Services Program              | X                        | X  |     |    |
| 4. Provide outreach and case management to Hispanic families through bilingual staff in Children's Medical Services program   |                          | X  |     |    |
| 5. Partner with MD AAP and PPMD to support developmental screening trainings for pediatric and family practitioners, including coding and reimbursement   |                          |    |     | X  |
| 6. Work with The Parents' Place of Maryland and other stakeholders to continue with the Community of Care Consortium for CYSHCN in Maryland that promotes and supports adequate insurance and financing |                          |    |     | X  |
| 7. Continue data analysis and dissemination of from the 2010 Maryland Parent Survey findings regarding adequacy of insurance and financial impacts on families of Maryland                              |                          |    |     | X  |
| 8.  |                          |    |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

#### **b. Current Activities**

In FY12 OGCSHCN reorganized its overall strategic plan around the 6 core outcomes; and identified the assembly of a workgroup to focus on improving adequacy of private and public health insurance coverage for CYSHCN to minimize financial impact on families. Subgoals include outreach to Latino families of CYSHCN (who are the most likely subgroup of CYSHCN to lack adequate insurance); a Medicaid buy-in cost/benefit analysis for Maryland, and increased collaboration with Medicaid to identify strategies for better reimbursement and coverage. Two quarterly CoC meetings focused on adequate insurance and financing. In FY12 PPMD and OGCSHCN released 6 Unmet Needs data sheets that were disseminated statewide and include data on insurance and financing; an Adequate Insurance Fact Sheet based on 2009-10 NS-CSHCN data was developed and disseminated by OGCSHCN. CMS has been unable to update its billing system due to a lack of resources but would like to work toward an electronic payment system - crucial as some facilities decline payment that requires only paper claims to file, decreasing the number of providers that can be accessed by families within the program. CMS staff advocate for CSHCN in the program and work with hospital billing staff/insurance providers to pay claims and sometimes to cover insurance premiums for CSHCN who qualify for MHIP (more cost effective to cover such premiums than to pay for individual services.)

### c. Plan for the Coming Year

The activities described above will continue. During FY12, OGCSHCN conducted a presentation and discussion about adequate insurance and financing to the CoC at a quarterly meeting. The next quarterly meeting focused on how the Affordable Care Act and health care reform efforts in Maryland will impact CYSHCN, with a presentation from a Maryland Legal Aid employee who also serves on Maryland's health care reform committee. A major conclusion of the CoC following her presentation was that, while there will be some improvements for CYSHCN and their families around insurance and financing as a result of health care reform, due to ERISA exemptions and other issues the majority of families of CYSHCN in Maryland will not see major relief as a result of reform. She also discussed Maryland's preparations for Health Insurance Exchanges (HIE) and that workgroups were looking for consumer involvement; as a result a parent applied for and was selected to serve on a HIE workgroup. PPMD presented about catastrophic illness relief funds in other states, and the CoC decided to pursue such a fund in Maryland as their first major activity for their group for networking, outreach, education, advocacy, and legality around financing. Work on this will begin in FY13. The CoC, sustained through OGCSHCN Title V funding, will continue to look for additional opportunities to positively impact this core outcome.

Analysis from the 2010 Maryland Parent Survey shows that, among responding families with at least one CYSHCN (n = 772 families): 54.5% report that their child's insurance does not pay for all health services needed; 12.7% report that their child was uninsured at some point in the 12 months prior to the survey; 37.7% had CYSHCN whose conditions cause family members to cut back or stop working; and 42.5% report having to pay \$1000 or more in out-of-pocket medical expenses per year per child. Plans for additional analyses of the 2010 Maryland Parent Survey include looking for significant differences in all survey responses among families and CYSHCN with different types of insurance as well as a regional analysis of insurance and unmet needs issues. Analyses will be conducted by OGCSHCN's graduate research assistant during FY13 and findings will be disseminated to stakeholders through the CoC and other OGCSHCN partners.

OGCSHCN partnered with PPMD in applying for a HRSA State Planning Grant to develop a statewide plan for improving the service system for children with autism spectrum disorder and other developmental disabilities. This grant was awarded and work began in FY12 and will continue throughout FY13 -- the needs assessment includes a section on adequate insurance and financing and the framework for the plan is the six core outcomes, including adequate insurance and financing. This core outcome was identified as a top priority need for several regions of the state and will be a primary focus of the statewide plan to be developed through the planning grant.

**Performance Measure 05:** *Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| Annual Objective and Performance Data | 2007 | 2008                    | 2009                    | 2010                    | 2011                    |
|---------------------------------------|------|-------------------------|-------------------------|-------------------------|-------------------------|
| Annual Performance Objective          | 75.5 | 89.5                    | 89.7                    | 89.9                    | 90.1                    |
| Annual Indicator                      | 89.3 | 89.3                    | 89.3                    | 89.3                    | 65.1                    |
| Numerator                             |      |                         |                         |                         |                         |
| Denominator                           |      |                         |                         |                         |                         |
| Data Source                           |      | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | NS-<br>CSHCN<br>2009-10 |



|   |             |             |             |             |             |
|---|-------------|-------------|-------------|-------------|-------------|
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |             |             |             |             |
| Is the Data Provisional or Final?   |             |             |             | Final       | Final       |
|   | <b>2012</b> | <b>2013</b> | <b>2014</b> | <b>2015</b> | <b>2016</b> |
| Annual Performance Objective  | 65.1        | 65.1        | 65.1        | 72          | 75          |

#### **Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were revisions to the wording, order, and number of questions used to generate this indicator for the 2005-06 CSHCN survey. The questions were also revised extensively for the 2009-2010 CSHCN survey. Therefore, none of the three rounds of the surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

#### **Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were revisions to the wording, ordering and the number of the questions used to generate the NPM05 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #05.

#### **Notes - 2009**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were revisions to the wording, ordering and the number of the questions used to generate the NPM05 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #05.

#### **a. Last Year's Accomplishments**

According to the 2009-10 National Survey of CSHCN (NS-CSHCN), 65.1% of Maryland families of CYSHCN report needed services for their CSHCN are community-based and easy to use; this is the same for families nationwide who report meeting this outcome (ETUCBS). Maryland ranks 29th in the nation. Hispanic CSHCN and those with emotional, behavioral or developmental issues are less likely to meet this outcome.

During FY11 OGCSHCN developed plans for a new statewide resource database and hired staff to research resources for CYSHCN and families to increase the effectiveness of the Children's Resource Line. OGCSHCN's online county-by-county resource map was updated and restored to full functionality.

OGCSHCN supports selected outreach specialty clinics throughout the state, including genetics and endocrinology clinics. In FY11, an estimated 1084 individuals were served in 16 specialty outreach clinics for CYSHCN. Local health departments reported that Kennedy Krieger discontinued several clinics in rural areas of the state, including developmental pediatrics, causing difficulties for families who need those services. OGCSHCN has continued its efforts to address the need for assistance with "navigating the system", providing grant funding to academic centers in Maryland and Washington, D.C. to support a Resource Liaison or similar

personnel at each center to assist families of CYSHCN to locate needed resources in the centers and in the community. The ASK program at the University of MD places one nurse in the pediatric primary clinic to help coordinate care for children with medically complex needs. At Children's National Medical Center (CNMC), a resource liaison and a parent navigator work as part of the Complex Care Program (CCP.) In FY11, the CCP saw 112 children and provided information about a variety of community resources to their families, and 106 families received parent navigator services (this does not include children seen in the hospital only.) The Resource Finder program at Kennedy Krieger is funded in part by OGCSHCN. In FY11 they fielded 1477 inquiries from caregivers, consumers, and providers. The most frequently requested information, by a large margin (57%) was regarding providers and services.

In FY11, grants from the OGCSHCN funded gap-filling care coordination for CYSHCN in a number of jurisdictions; at least 958 children were served by staff in at least 13 Local Health Departments. OGCSHCN also continued to provide funding to The Parents' Place of Maryland (PPMD) to expand its Family-to-Family Health Information and Education Center, which operates an information and referral line as well as a network of parent representatives throughout the state who are available to work one-on-one with families of CYSHCN. A similar "Children's Resource Line" is answered by staff at the OGCSHCN. PPMD conducted "Finding Community Resources" and "Managing the Maze" workshops for parents across the state.

OGCSHCN continues its partnership with PPMD in the Maryland Community of Care (CoC) Consortium for CSHCN. As part of its ongoing reorganization, in FY11 OGCSHCN hired a staff person to work on the State Implementation grant in addition to other projects, enabling OGCSHCN to contribute more staff time to the CoC and thus to ease of use of the system of care for CYSHCN in Maryland. In FY11, the CoC was funded through a State Implementation grant awarded to PPMD, and is a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems that holds quarterly meetings and identifies priorities, including ETUCBS. The CoC inherently supports improvements to this core outcome by providing a forum for networking and communication among various stakeholder groups and system components (i.e. physicians, community providers, families, government, etc.) on a quarterly basis, and on a continual basis through the CoC website. During the inaugural summit for CoC in November 2008, the group identified barriers to CYSHCN system navigation and disparities in accessing services in communities in Maryland. These issues were revisited during FY11 and the group identified additional barriers including that there is no single point of entry into the system for families. The group brainstormed strategies agreed that counties need ways to network between providers and there needs to be a mechanism for sharing of resources b/t counties.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Support selected subspecialty outreach clinics throughout the state  | X                        |    |     | X  |
| 2. Support a Resource Liaison or similar personnel at 3 Centers of Excellence, and The Parents' Place of Maryland for outreach, information, and referral to families and providers |                          | X  |     | X  |
| 3. Support the operation of 2 medical day care centers serving medically fragile infants and young children   | X                        | X  |     |    |
| 4. Support the local health departments and parent organizations to provide a variety of respite services to families of CYSHCN   |                          | X  |     |    |
| 5. Fund gap-filling care coordination for CYSHCN through local health departments, and make needed quality improvements to the system   |                          | X  |     | X  |
| 6. Work with The Parents' Place of Maryland and other   |                          |    |     | X  |

|   |  |  |  |   |
|---|--|--|--|---|
| stakeholders to continue with the Community of Care Consortium for CYSHCN in Maryland that promotes and supports easy to use, community-based service systems |  |  |  |   |
| 7. Conduct regional meetings for local health departments to develop collaborative relationships  |  |  |  | X |
| 8. Conduct Centers of Excellence and Community grantee meeting to develop collaborative relationships and to educate partners about core outcomes for CYSHCN. |  |  |  | X |
| 9.  |  |  |  |   |
| 10.   |  |  |  |   |

#### **b. Current Activities**

In FY12 OGCSHCN reorganized its overall strategic plan around the 6 core outcomes; identified activities to support ETUCBS, including a partnership with Maryland Center for Developmental Disabilities (MCDD) for regional community resource mapping to increase access to community-based services and for development of an OGCSHCN resource database for families and providers. OGCSHCN hired a Resource Coordinator (a parent of CYSHCN) to provide resource coordination, education, training to families of CYSHCN, to run the Children's Resource Line and keep the resources database up-to-date. OGCSHCN continued to support local health departments for respite care and care coordination close to home as well as specialty clinics in the Maryland and Washington, D.C. region. OGCSHCN will continue to promote collaborative relationships among LHDs to maximize services, especially in rural, underserved communities. OGCSHCN and PPMD staff met with other grantees to coordinate activities. Regional meetings were conducted by OGCSHCN staff in 2011; topics focused on the community resource mapping project, resource database, health care notebooks and flash drives, and identifying regional needs, priorities, and opportunities for regional LHD collaboration. PPMD and OGCSHCN released 6 Unmet Needs data sheets to show regional differences in needs/outcomes among families of CYSHCN and disseminated statewide; an ETUCBS Fact Sheet based on 2009-10 NS-CSHCN data was developed and disseminated by OGCSHCN.

#### **c. Plan for the Coming Year**

The activities described above will continue. In FY11, OGCSHCN held a mandatory retraining for all of its grantees to inform them of new state Title V priorities, findings from the Title V 2010 Needs Assessment, new grant reporting requirements, and an information session on core outcomes for CYSHCN. Grantees networked and identified areas of common focus and possible collaboration in the future; this activity was repeated in FY12 with an additional focus on family-centered care and will be conducted again for FY13 grantees. Meetings of this type will be held yearly by OGCSHCN to promote cooperation, coordination and networking among grantees. OGCSHCN plans to start quarterly conference calls on various topics for both LHD and other grantees, as well.

OGCSHCN will fund the CoC in FY13, because the federal D70 grant ended in FY12, and thus will support the continuance of the above activities through the CoC, including quarterly meetings, which help to strengthen the linkages between services and providers in the system of care for CYSHCN. In FY12, the CoC began funding a mini-Consortium in the Eastern Shore region of Maryland, where there are very few community-based services for CYSHCN. This mini-consortium is identifying existing services and gaps and building new partnerships in order to creatively fill gaps and bring needed services to families in that region. In FY13 the CoC will continue to fund the Eastern Shore Consortium and plans to start a Consortium for Western Maryland, another rural area in which there are very few community-based services for CYSHCN. Hispanic CYSHCN are less likely to achieve this core outcome; PPMD, through D70 funding, started a Latino Family Support Consortium for Maryland CYSHCN -- this group has met quarterly during FY12 and consists of community providers, families, and local and state government representatives and is designed to increase awareness and partnerships. This activity will also continue in FY13 under OGCSHCN CoC funding. The CoC and OGCSHCN will

continue to look for opportunities to positively impact this core outcome.

**Performance Measure 06:** *The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| Annual Objective and Performance Data   | 2007        | 2008                    | 2009                    | 2010                    | 2011                    |
|---|-------------|-------------------------|-------------------------|-------------------------|-------------------------|
| Annual Performance Objective  | 12          | 38                      | 38.5                    | 39                      | 39.5                    |
| Annual Indicator  | 37.5        | 37.5                    | 37.5                    | 37.5                    | 36.8                    |
| Numerator   |             |                         |                         |                         |                         |
| Denominator   |             |                         |                         |                         |                         |
| Data Source   |             | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | SLAITS<br>2005-<br>2006 | NS-<br>CSHCN<br>2009-10 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                         |                         |                         |                         |
| Is the Data Provisional or Final?   |             |                         |                         | Final                   | Final                   |
|   | <b>2012</b> | <b>2013</b>             | <b>2014</b>             | <b>2015</b>             | <b>2016</b>             |
| Annual Performance Objective  | 36.8        | 36.8                    | 36.8                    | 40.5                    | 43                      |

#### Notes - 2011

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the 2 surveys are not comparable for NPM 6, and findings from the 2005-06 survey may be considered baseline data. However, the same questions were used to generate the NPM 6 indicator for the 2009-2010 survey. Therefore, the 2005-2006 and 2009-2010 surveys can be compared.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

#### Notes - 2010

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate the NPM06 indicator for the 2005-2006 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the two surveys are not comparable for PM #06 and the 2005-2006 may be considered baseline data.

#### Notes - 2009

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate the NPM06 indicator for the 2005-2006 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the two surveys are not comparable for PM #06 and the 2005-2006 may be considered baseline data.

#### **a. Last Year's Accomplishments**

According to the 2009-10 National Survey of CSHCN (NS-CSHCN), only 36.8% of Maryland families of YSHCN report that youth are receiving all needed services for successful transitions to adulthood, compared to 40% of YSHCN nationally; Maryland ranks 40th in the nation. This continues the trend of Maryland's slight climb in state rankings on this indicator -- from 44th in 2001 to 42nd in 2005-06. Hispanic and African American YSHCN as well as YSHCN without adequate insurance are less likely to meet this outcome.

The OGCSHCN reorganization has allowed for the creation of a Transition Coordinator position, filled during FY11.

OGCSHCN continued to promote successful health care transition for youth with sickle cell disease (SCD) and diabetes (DM) through support of transition clinics at the Johns Hopkins Hospital. Youth with SCD 18 to 24 y/o are cared for jointly by the pediatric and adult hematologists in the transition clinic in the Department of Internal Medicine, prior to transfer of care to the adult hematology clinic. In FY11, the SCD transition clinic provided 337 visits to 63 patients. The transition clinic for DM targets patients in their last year of high school; parents and youth are introduced to the adult endocrinologist at the transition clinic who meets with the patients and their parents both with and without the pediatric endocrinologist. In FY11, the clinic held a total of 31 transition clinic sessions.

OGCSHCN funded Kennedy Krieger's (KKI) Transition Lecture Series, completing its 9th successful year. A total of 178 youth, families and providers attended seven lectures. Topics included: "Community Works Project: How to find respite care providers"; "College and University Disability Support Services"; "Human Sexuality"; and the most well-attended lecture, "Low Intensity Support Services." Lectures are videotaped; copies are loaned to families and are available at the Regional Resource Center for Children with Special Needs on the Eastern Shore. In June 2011, KKI held a test web conference lecture attended by 21 participants in order to identify ways to reach more participants with the transition lecture series.

The Children's Medical Services Program (CMS) within OGCSHCN pays for specialty care for YSHCN enrolled in the program until the age of 22 years. Care may be covered until age 25 in some circumstances. The CMS Program staff work with YSHCN/families to assist them with transitioning into programs for adults well in advance of the time when they will lose their eligibility for the CMS program.

PPMD, partnering with the OGCSHCN, received a State Implementation Grant for Integrated Community Systems for CYSHCN. OGCSHCN staff provided leadership and staff support to develop the Maryland Community of Care (CoC) Consortium for CYSHCN. The inaugural summit in 2008 was attended by over 100 physicians, other professionals, and families. Participants worked in small groups, including a group focused on transition to adulthood. As a result of the Summit, The Maryland State Department of Education (MSDE) was supposed to include information about health transition in the manual which is provided to students with an IEP and their families at their transition planning meeting, but had not yet done so; in FY11 OGCSHCN staff submitted health care transition materials to MSDE for inclusion in the annual update of their Transition Planning Guide. An OGCSHCN staff person partnered with the Maryland CMCH and PPMD to develop a statewide survey of parents of CYSHCN as part of the 2010 Title V Needs Assessment. Several questions on the survey focused on youth transition to adulthood. Due in part to the data collected from this survey, as well as the overall Needs Assessment process,

youth transition to adulthood was identified as a state-level priority. A yearly survey of parents of transition-age youth is planned for FY11 through FY15 to guide planning and measure impact of state activities around this priority. This survey was developed by OGCSHCN, PPMD, MSDE, and the Maryland Center for Developmental Disabilities (MCDD) with input from the Maryland Department of Disabilities and piloted during FY11.

In FY11 OGCSHCN planned to continue its involvement with the Statewide Steering Committee on Services for Adults with Sickle Cell Disease as a mechanism for raising awareness of health care transition issues, but unfortunately after several meetings this group once again was unable to sustain momentum.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Support transition clinic activities including clinics for youth with sickle cell disease and youth with diabetes  |                          | X  |     |    |
| 2. Support monthly Transition Lecture Series for youth, families and providers hosted by Kennedy Krieger  |                          | X  |     | X  |
| 3. Develop and pilot the Transitioning Youth Parent Survey.   |                          |    |     | X  |
| 4. Provide payment for specialty care and related services for uninsured YSHCN until age 22 years through Children's Medical Services Program   | X                        | X  |     |    |
| 5. Partner with The Parents' Place of Maryland and the Center for Maternal and Child Health to analyze data gathered from Maryland families of YSHCN on parent participation in transition planning |                          |    |     | X  |
| 6. Promote youth transition to adulthood as a state-level priority for Maryland YSHCN and continue strategic planning to improve this outcome.  |                          |    |     | X  |
| 7. Plan for 3 regional Health Care Transition Conferences in FY12   |                          |    |     | X  |
| 8. Sponsor and present on health care transition at Maryland's Interagency Transition Council's annual conference.  |                          |    |     | X  |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

#### **b. Current Activities**

The OGCSHCN Transition Coordinator hired in FY11 left and the position was quickly filled with an experienced project manager/health educator who is establishing strategic partnerships with various agencies and organizations (The Arc, Maryland Division of Rehabilitation Services, Department of Developmental Disabilities, MCDD, and MSDE) to develop a statewide strategic plan for health care transition (HCT). OGCSHCN supported an interagency youth transition conference; staff presented about HCT. OGCSHCN is identifying resources for transition to include in the Resource Database so that youth, families and providers can locate existing services. MSDE is including information on HCT in the MSDE Transition Planning Handbook as an additional handout. OGCSHCN continued to fund HCT clinics and the transition lecture series. OGCSHCN/PPMD conducted the Parent Survey for Transitioning Youth. A Youth Transition Fact Sheet based on 2009-10 NS-CSHCN data was developed/disseminated by OGCSHCN. OGCSHCN/PPMD conducted 3 HCT Conferences for a total of 94 participants (families, youth and providers) in Central and Western Maryland and on the Eastern Shore. Participants received HCT resources and two training tracks were offered -- one for families and one for youth. Families were trained on topics including HCT planning and social security

benefits, and youth received training on managing their own health care and the changes their bodies go through in puberty and young adulthood.

### **c. Plan for the Coming Year**

The above activities will continue. Preliminary goals for the statewide HCT strategic plan include improving clinical HCT services for YSHCN; developing a list of medical providers who treat young adults with SHCN; identifying and adapting resources to support youth, families and providers to plan for HCT; providing technical assistance around HCT to OGCSHCN grantees who work with YSHCN; ensuring the participation of YSHCN as members of youth advisory councils and groups in Maryland; and improving state and local capacity to collect, share, analyze and disseminate HCT data and information to evaluate transition program goals. The Transition Coordinator will disseminate the plan to partners in other agencies and organizations for feedback and suggestions, and portions of the plan will be implemented during FY13. Existing clinical HCT programs run by OGCSHCN grantees will be explored and technical assistance will be offered to share best practices with other grantees. OGCSHCN plans to present on HCT at several statewide and local interagency conferences and trainings for youth transition.

OGCSHCN will also continue to promote inclusion of HCT resources and materials in various state guides and manuals for YSHCN, including the Developmental Disabilities Administration's transition manuals for youth.

Data gathered from the FY12 Parent Survey for Transitioning Youth will be analyzed, shared and disseminated and the survey will be conducted again during FY13. Findings from the FY12 analysis will be used to guide program planning and activities and for reporting for the state level priority performance measure. The state performance measure is related to parents' participation in transition planning for their YSHCN.

The CoC, through OGCSHCN Title V funding, will continue to look for opportunities to positively impact this core outcome. At a quarterly meeting in FY11, attendees reviewed strategies developed at the 2008 Summit to increase the achievement of successful youth transition to adulthood in Maryland. Progress on strategies was reviewed and next steps and appropriate partners to pursue strategies were identified. A strong focus, along with other initiatives, should be on youth and family training around transition planning, while at the same time consolidating transition resources and information in a user/family-friendly accessible database. The OGCSHCN Transition Coordinator is building on the success of the FY12 HCT Conferences and planning three more regional health care transition conferences with PPMD to take place during FY13. Plans to add an additional training track for providers are being considered. OGCSHCN will continue to enhance its statewide resource database to include a comprehensive catalogue of transition resources for families.

There are plans to make KKI's Transition Lecture series widely available throughout the state by posting videos of lectures on websites and enabling web and audio conferencing during live lectures.

**Performance Measure 07:** *Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.*

#### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance Objective                 | 83          | 86.5        | 93          | 83          | 80          |
| Annual Indicator                             | 92.4        | 73.6        | 77.9        | 65.9        | 65.9        |

|   |             |                        |                        |                       |                       |
|---|-------------|------------------------|------------------------|-----------------------|-----------------------|
| Numerator   | 206988      | 163837                 | 178949                 | 145026                | 145026                |
| Denominator   | 224013      | 222604                 | 229716                 | 220071                | 220071                |
| Data Source   |             | MMWR Report, CDC, 2008 | MMWR Report, CDC, 2009 | MMWR Report, CDC 2010 | MMWR Report, CDC 2010 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                        |                        |                       |                       |
| Is the Data Provisional or Final?   |             |                        |                        | Final                 | Provisional           |
|   | <b>2012</b> | <b>2013</b>            | <b>2014</b>            | <b>2015</b>           | <b>2016</b>           |
| Annual Performance Objective  | 70          | 70                     | 70                     | 70                    | 70                    |

#### Notes - 2011

Source: Percentage is based on data from the MMWR Report "National State and Local Area Vaccination Coverage Among Children Aged 19-35 months, US. 2010".

This percentage was applied to the estimated number of children between the ages of 1-3 in 2010 (denominator) based on U.S. Census Bureau Population Estimates to create a numerator. 4:3:1:3:3:1 series used to calculate coverage rate. Data for 2011 not currently available

#### Notes - 2010

Source: Percentage is based on data from the MMWR Report "National State and Local Area Vaccination Coverage Among Children Aged 19-35 months, US. 2010".

This percentage was applied to the estimated number of children between the ages of 1-3 in 2010 (denominator) based on U.S. Census Bureau Decennial Census to create a numerator. 4:3:1:3:3:1 series used to calculate coverage rate.

#### Notes - 2009

Source: Percentage is based on data from the MMWR Report "National State and Local Area Vaccination Coverage Among Children Aged 19-35 months, US. 2009". This percentage was applied to the estimated number of children between the ages of 1-3 in 2009 (denominator) based on U.S. Census Bureau Population Estimates to create a numerator. 4:3:1:3:3:1 series used to calculate coverage rate

#### a. Last Year's Accomplishments

According to the MMWR Report from the Centers for Disease Control and Prevention (CDC)'s sponsored National Immunization Survey (NIS), in 2010, reportedly 65.9% of Maryland children ages 19-35 months were fully immunized as defined by the 4:3:1:3:3:1 series. This percentage is below the national average for this time period as well as Maryland's target goal of 80% for this measure.

Immunization outreach activities were included in Maryland's Title V funded early childhood grant activities. A priority of the Early Childhood Health Plan completed by the Title V Program is to increase access to medical homes for young children. Immunizations are an important component of well child care to be promoted within the medical home. Education about the importance of immunizations as well as any new Maryland vaccination guidelines are part of early childhood health outreach efforts.



The DHMH Center for Immunization is largely responsible for statewide immunization activities in Maryland. Ongoing activities to promote early childhood immunization in FY 2011 included the distribution of immunization educational materials to the parents of every child born in the State, administration of the State's immunization registry - ImmuNet, and operation of the Maryland Vaccines for Children (VFC) Program. The Center conducts disease surveillance activity and monitoring; and provides immunization health education and resources through the Maryland Partnership for Prevention.

The VFC Program allows enrolled physicians to provide all routinely recommended vaccines, at no cost, to children 18 years old and younger who are Medicaid enrolled; uninsured; underinsured or Native American/Alaskan Native. There are currently approximately 800 enrolled providers practicing at 1,000 public and private practice vaccine delivery sites throughout the State. Immunization Excellence Awards are given to VFC providers, who demonstrate excellence in all critical areas reviewed by the VFC Program, including immunization coverage rates of two year olds; and pediatric practice standards.

ImmuNet, the State's immunization registry, began implementation in June 2004. The registry provides a consolidated vaccination record for children enrolled, provides reminder and recall notices, and prints forms for schools, camps, and day care. To date, ImmuNet contains more than 1,000,000 patient records and 12,000,000 vaccinations and is currently used in more than 900 provider offices.

Title V also continued to support local health department efforts to inform consumers, communities and providers about the importance of immunizations. Although the majority of children are immunized in private physician offices, several local health departments continued to offer immunization clinics serving children in underserved areas of the State in 2011. MCH nursing staff in local health departments educated families about the importance of immunizations during home visiting and early childhood programs as part of a comprehensive approach to well child care. Educational materials to promote awareness of the need for immunization continued to be a part of all MCH outreach activities. WIC Program staff determined the immunization status of their clients at every encounter.

Title V funds continue to directly support Baltimore City's Immunization Registry, developed independently of ImmuNet. The City's Registry maintains a database of immunization and demographic information on Baltimore City children collected from pediatric providers. To date, ImmuNet contains more than 1,000,000 patient records and 12,000,000 vaccinations and is currently used in more than 900 provider offices.

The Maryland Partnership for Prevention (MPP), the state's immunization coalition, began offering a Practice Makes Perfect Immunization Training that provides health professionals with comprehensive resources to support promotion and administration of childhood immunizations. This half day training session provides an overview of topics that are important to safely and effectively provide immunizations, including vaccine recommendations for children, adolescents, and adults; child care and school immunization requirements; vaccine storage and handling; and the Maryland Vaccines For Children Program. In 2011, the Partnership asked Governor O'Malley to declare April as Maryland Infant Immunization Month.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Distribute education materials to parents of every newborn in the state that includes information on immunizations (Center for Immunizations) |                          |    | X   |    |

|  |   |   |   |   |
|--|---|---|---|---|
| 2. Fund local health department immunization clinic and outreach/ education activities   | X |   | X |   |
| 3. Continue to expand the state's immunization registries  |   | X |   |   |
| 4. Provide insurance coverage for immunization registries, Immunet (statewide) and Baltimore City registry. Title V will support the Baltimore City registry       |   | X |   |   |
| 5. Administer the Vaccines for Children Program (Center for Immunizations)   |   |   |   | X |
| 6. Promote immunizations through home visiting and early childhood programs. Promote access to medical homes for all children through Early Childhood Health Grant |   |   | X |   |
| 7. Screen for immunization status in WIC and other MCH programs  |   |   | X |   |
| 8. Participate in MD Immunization Partnership  |   |   |   | X |
| 9. Provide outreach and education to the general public and health care providers to improve immunization levels   |   |   | X | X |
| 10.  |   |   |   |   |

#### **b. Current Activities**

In March 2012, DHMH received an 18 month grant from the Robert Wood Johnson Foundation to conduct a Quality Improvement project around the integration of public health services across MCH, environmental health and chronic disease. The Office of Population Health in collaboration with the Maternal and Child Health Bureau, the Infectious Disease Bureau and the Cancer and Chronic Disease Bureau are identifying ways to increase referral follow up for Maryland WIC clients in pilot sites in two counties. This initiative aims to define the systems and procedures needed to increase data sharing between WIC and public health programs to increase the access of WIC clients to public health resources such as child lead testing, child immunizations, smoking cessation programs and access and information regarding family planning.

The Title V Program is advising project staff on ways to Increase WIC children's vaccination coverage for recommended vaccines and enhancing the WIC staff's ability to accurately assess the immunization status of WIC participants. Finally, the project aims to increase the utilization of vaccination services by those WIC participants who require follow up.

#### **c. Plan for the Coming Year**

Ongoing activities for 2013 will include:

1. Distributing educational materials to parents of every newborn in the State that includes information on immunizations (Center for Immunizations)
2. Funding local health department immunization clinics and outreach/education activities (Center for Immunizations).
3. Continuing to expand the State's immunization registries, Immunet (statewide) and the Baltimore City registry. Title V supports the Baltimore City registry.
4. Providing insurance coverage for immunizations through Medicaid and MCHP.
5. Administering the Vaccines for Children Program (Center for Immunizations)
6. Promoting immunizations through home visiting and early childhood programs, including the newly developed the Maryland MIECHV Program.
7. Promoting access to medical homes for all children through the Early Childhood Health (ECCS) Grant.
8. Screening for immunization status in WIC and other MCH programs.
9. Participating on the State's immunization partnership, the Maryland Partnership for Prevention.
10. Providing outreach and education to the general public and health care providers to improve immunization levels.

11. Working with the Maryland State Department of Education, Office of Child Care, to increase compliance with childcare immunization requirements.
12. Continuing to work with the Office of Population Health on the RWJ sponsored Quality Improvement Project.

**Performance Measure 08:** *The rate of birth (per 1,000) for teenagers aged 15 through 17 years.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>                                   | <b>2009</b>                                   | <b>2010</b>                                   | <b>2011</b>                                   |
|---|-------------|---|---|---|---|
| Annual Performance Objective  | 16.4        | 16.4  | 17.5  | 17  | 16  |
| Annual Indicator  | 18.3        | 17.4  | 16.3  | 13.5  | 13.5  |
| Numerator   | 2200        | 2055  | 1879  | 1601  | 1601  |
| Denominator   | 120146      | 118208  | 115606  | 118328  | 118328  |
| Data Source   |             | MD Vital Statistics, 2008; U.S. Census Bureau | MD Vital Statistics, 2009; U.S. Census Bureau | MD Vital Statistics, 2010; U.S. Census Bureau | MD Vital Statistics, 2010; U.S. Census Bureau |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |   |   |   |   |
| Is the Data Provisional or Final?   |             |   |   | Final   | Provisional                                   |
|   | <b>2012</b> | <b>2013</b>                                   | <b>2014</b>                                   | <b>2015</b>                                   | <b>2016</b>                                   |
| Annual Performance Objective  | 13          | 13  | 13  | 12  | 12  |

**Notes - 2011**

Source: Maryland Vital Statistics Administration, 2010 Annual Report; population (denominator) from U.S. Census Bureau Population Estimates. Data for 2011 is currently unavailable.

**Notes - 2010**

Source: Maryland Vital Statistics Administration, 2010 Annual Report; population (denominator) from U.S. Census Bureau Population Estimates.

**Notes - 2009**

Source: Maryland Vital Statistics Administration, 2009 Annual Report; population (denominator) from U.S. Census Bureau Population Estimates.

**a. Last Year's Accomplishments**

Maryland's birth rate for teens aged 15-19 years of all races declined from 32.7 per 1000 births in 2008 to 27.2 per 1000 births in 2010. However in 2010, the birth rate among varied by race/ethnicity and geography. Hispanic teens (52.7) had the highest birth rate in 2010, followed by African American (40.5) teens and White, non-Hispanic teens (16.1). However, teen birth rates continued their decline across all racial/ethnic groups in 2010.

In 2011, teen pregnancy prevention efforts were addressed and coordinated through the Maryland Family Planning Program, the Maryland Abstinence Education Program and the Maryland Personal Responsibility and Education (PREP) Program. The State Title V Adolescent Health Coordinator maintained an adolescent health/teen pregnancy prevention listserv to update members on issues of concern and monitored grants to several jurisdictions with high need.

In FY 2011, the Family Planning Program served a total of 18,146 teens ages 15-19 and 1,405 teens under the age of 15. More than 2,400 of these teens were enrolled in the one of the State's three Healthy Teen and Young Adult (HTYA) sites located in Baltimore City and Anne Arundel and Prince George's counties. HYTA clinical services are offered through model clinics which embrace a comprehensive, holistic approach to health care. The program extends special services to teens and young adults who face social, cultural, institutional, and financial barriers to care.

Last year, the Center for Maternal and Child Health began receiving funding for two new Affordable Care Act programs - Abstinence Education and Personal Responsibility and Education (PREP). A PREP Coordinator was hired in August 2011 to oversee program activities. PREP program funds were targeted to communities most at risk for high teen pregnancy and sexually transmitted infection rates. This included eleven jurisdictions with teen birth rates that were higher than the statewide average in 2005-2009. The Baltimore City Health Department, in partnership the Healthy Teen Network, the University of Maryland School of Social Work, and Planned Parenthood of Maryland, received PREP funds to administer a program targeted at foster care youth and their care givers. This program is using the Power through Choices curriculum. The State also issued a competitive RFA to award the remaining funds. These funds were awarded to subgrantees in FY 2012.

Abstinence education funds were offered statewide to jurisdictions indicating an ability to meet the required federal match. The Maryland Abstinence Education and Coordination Program awarded funds to six jurisdictions to implement the abstinence education program according to federal guidelines. The Title V Adolescent Health Coordinator oversees the Abstinence Education Program.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Provide comprehensive family planning and reproductive health services to approximately 25,000 teens annually   | X                        |    |     |    |
| 2. Fund 3 Health Teen and Young Adult programs promoting a holistic approach to teen pregnancy prevention  | X                        | X  |     |    |
| 3. Apply and administer the federal abstinence education grant. Fund abstinence education programming through grants to local health departments and other community based groups. |                          | X  |     |    |
| 4. Conduct training and education events including a conference for providers, adolescents and parents/ caregivers to promote abstinence and reduce teen pregnancy                 |                          | X  |     |    |
| 5. Collaborate with other agencies to promote positive youth development   |                          |    |     | X  |

|                            |  |  |  |   |
|----------------------------|--|--|--|---|
| 6. Monitor data and trends |  |  |  | X |
| 7.                         |  |  |  |   |
| 8.                         |  |  |  |   |
| 9.                         |  |  |  |   |
| 10.                        |  |  |  |   |

#### **b. Current Activities**

This year, the PREP Program awarded funds to nine sub-grantees including Baltimore City. The PREP Program also hired and worked with a vendor, the After School Institute to provide curriculum training to six of the nine grantees opting to use Promoting Health Among Teens --C as their curriculum choice. This vendor will assist the PREP Program with quarterly meetings and trainings for the subgrantees throughout the year and work with the Program to convene an Advisory Group.

The Abstinence Education Program awarded funds to seven local health departments. An evaluator was also hired to assist with the Program evaluation activities.

#### **c. Plan for the Coming Year**

MCH plans for the coming year include:

- . Continuing to provide family planning services and reproductive health programs directed at adolescent pregnancy prevention including services at Healthy Teen and Youth Adult sites;
- . Continuing to work with Abstinence Education and PREP grantees to implement evidence based programs. A major focus for 2013 will be on data collection, fidelity monitoring and quality improvement;
- . Holding quarterly meetings with PREP and Abstinence grantees to provide needed programmatic updates and trainings to increase State capacity to offer quality programming. When appropriate, meetings/trainings are coordinated across programs;
- . Establishing a State PREP Advisory Council; and
- . Monitoring and analyzing data and trends to update a State Plan for Teen Pregnancy and Sexually Transmitted Disease Prevention.

Next year, grantee training will focus on data collection, fidelity monitoring and quality improvement, and positive youth development principles. In addition, the national PREP Program is promoting the use of trauma informed care by its grantees. Following the receipt of additional guidance from the national program, trainings will be developed to inform subgrantees in Maryland.

**Performance Measure 09:** *Percent of third grade children who have received protective sealants on at least one permanent molar tooth.*

#### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance Objective                 | 30          | 42.5        | 52          | 43          | 43          |

|   |             |  |  |  |  |
|---|-------------|--|--|--|--|
| Annual Indicator  | 42.2        | 42.4   | 42.4   | 42.4   | 42.4   |
| Numerator   | 25466       | 25457  | 25457  | 25457  | 25457  |
| Denominator   | 60400       | 60040  | 60040  | 60040  | 60040  |
| Data Source   |             | Survey of Oral Health of MD School Children, 05-06 | Survey of Oral Health of MD School Children, 05-06 | Survey of Oral Health of MD School Children, 05-06 | Survey of Oral Health of MD School Children, 05-06 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |  |  |  |  |
| Is the Data Provisional or Final?   |             |  |  | Provisional  | Provisional  |
|   | <b>2012</b> | <b>2013</b>  | <b>2014</b>  | <b>2015</b>  | <b>2016</b>  |
| Annual Performance Objective  | 45          | 45   | 45   | 45   | 45   |

#### **Notes - 2011**

Source: University of Maryland Dental School, Survey of the Oral Health of Maryland School Children, 2005-2006 School Year. Data for 2011 is currently unavailable.

#### **Notes - 2010**

Source: University of Maryland Dental School, Survey of the Oral Health of Maryland School Children, 2005-2006 School Year. Data for 2010 is currently unavailable.

#### **Notes - 2009**

Source: University of Maryland Dental School, Survey of the Oral Health of Maryland School Children, 2005-2006 School Year. Data for 2009 is currently unavailable.

#### **a. Last Year's Accomplishments**

Access to oral health care is a critical problem for underserved and minority populations in Maryland. The 2005 - 2006 Survey of Oral Health Status of Maryland School Children (the most recent survey), conducted by the University of Maryland Dental School, found that 29.7% of third graders and 32.6% of Kindergarteners had untreated dental caries. Children residing on the Eastern Shore and in Southern Maryland had the highest rates of untreated tooth decay. Low-income, African-American and Hispanic children suffer even higher rates of tooth decay than White and upper-income children.

The Maryland Office of Oral Health has lead responsibility for oral health activities in Maryland. A Maryland Dental Action Coalition (MDAC) formed in 2010. MDAC is an independent, broad-based statewide coalition of individuals and organizations dedicated to improving the oral health of all Marylanders through increased prevention, education, advocacy, and access to oral health care. Title V continued to be represented on the Maryland Dental Action Coalition in 2011.

2011 was a very active year for oral health in Maryland. In May 2011, the Dental Action Coalition

along with the Secretary of Health and Mental and the Office of Oral Health released the first statewide Oral Health Plan. The 31 page Plan outlines a vision of improved oral health for all Marylanders by focusing on three key areas: Access to Oral Health Care, Oral Disease and Injury Prevention and Oral Health Literacy and Education. The five year plan (2011-2015) has specific goals, objectives and activities for the three key areas. Its development, lead by MDAC, involved many key individuals working in state and local government health care agencies, academic institutions, professional dental organizations, private practice, community-based programs, the insurance industry, and advocacy groups, as well as other important stakeholders and organizations.

Also in May 2011, the Pew Children's Dental Campaign released its annual 50 state report card. Maryland received an A and was rated as the top performing state in the nation for 2011 because it was the only state to meet seven of eight policy benchmarks developed by Pew.

Maryland was also awarded a \$1.2 million federal grant to develop and implement an Oral Health Literacy Campaign to prevent tooth decay in infants and children up to three years old. The campaign's goal is to reach Medicaid-enrolled mothers and guardians of this at-risk population early and often with the knowledge necessary to prevent tooth decay and improve their children's oral health.

A statewide Oral Health Summit was held in October 2011. Summit participants reviewed Maryland progress and successes as well as areas of continuing challenge and need. Background papers and commentaries from the Summit are published in the Winter 2012 supplement to the Journal of Public Health Dentistry.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Partner with the Office of Oral Health, Medicaid and other stakeholders to develop and sustain a statewide Oral Health Coalition focused on improving access to oral health care services and assisting with implementing recommendations                  |                          |    |     | X  |
| 2. Survey preschool and school aged children to ascertain and monitor oral health status needs  |                          |    |     | X  |
| 3. Fund and support a range of oral health services for children in local health departments including diagnostic, preventative, and restorative services. Title V supports services in Baltimore City. The Office of Oral Health supports services statewide | X                        | X  |     |    |
| 4. Plan and promote strategies to improve early childhood oral health   |                          |    |     | X  |
| 5. Provide insurance coverage for dental health services for children and pregnant women through Medicaid and MCHP  |                          |    |     | X  |
| 6. Administer a loan repayment program for dentists who serve low income populations (Office of Oral health)  |                          |    |     | X  |
| 7. Fund school based dental sealant programs  |                          |    |     | X  |
| 8. Promote the P.A.N.D.A. Project, a child abuse and prevention program that trains dentists to recognize abuse   |                          |    |     | X  |
| 9. Disseminate a Resource Guide that identifies discounted and low cost dental health services available to eligible Marylanders  |                          | X  |     |    |
| 10. Conduct a statewide pilot school sealant demonstration project in partnership with the University of Maryland Dental School to determine the most cost effective means to deliver sealants in school environments   | X                        | X  |     |    |

**b. Current Activities**

On behalf of the State's Early Childhood Advisory Council, the Early Childhood Program staff conducted focus groups with pediatric dentists in June 2012 to determine barriers to achieving a dental home for every child. The results are currently being analyzed and summarized for a report to the Council. Preliminary findings indicate provider concerns with low Medicaid reimbursement rates and a lack of parental awareness of the importance of early childhood dental care.

The Oral Health Literacy Campaign launched on June 4, 2012 and is currently in full swing. The campaign includes radio and TV advertising in four Maryland markets: Baltimore, Salisbury, Hagerstown and suburban DC. It also includes bus shelter advertising in the greater Baltimore metropolitan area, a direct mail campaign of 160,000 brochures mailed to Medicaid recipients and the distribution of 80,000 oral health kits through WIC, Head Start and the local Maryland health departments. All marketing materials is designed to drive viewers, listeners and readers to a website at [www.healthyteethhealthykids.org](http://www.healthyteethhealthykids.org) or a call center at 1-855-45-TEETH. The Campaign is working with partners statewide, including the Title V Program to distribute information, including 240,000 Healthy Teeth, Healthy Kids brochures.

**c. Plan for the Coming Year**

This coming year, the Title V MCH Program will continue:

- . Participating on various statewide alliances and coalitions that address oral health including participation on the Maryland Dental Action Coalition and the Oral Health Literacy Campaign Task Force;
- . Working with the Office of Oral Health, the Medicaid Program and MDAC to implement the State Oral Health Plan to improve the oral health of children in Maryland;
- . Collaborating with the Office of Oral Health in planning for the next statewide oral health survey of Maryland schoolchildren, specifically grades K and 3;
- . Assisting the Office of Oral Health in developing a formal surveillance system that includes data from the PRAMS database for pregnant women; and
- . Supporting local health efforts to improve access to oral health services for low-income children and pregnant women.

**Performance Measure 10:** *The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.*

**Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance Objective                 | 3           | 3.5         | 2.9         | 3           | 1.7         |
| Annual Indicator                             | 3.1         | 2.3         | 1.7         | 1.1         | 1.1         |
| Numerator                                    | 34          | 25          | 19          | 12          | 12          |
| Denominator                                  | 1107687     | 1099652     | 1115865     | 1110385     | 1110385     |



| Data Source   |             | MD Vital Statistics, 2008 | MD Vital Statistics, 2009 | MD Vital Statistics, 2010 | MD Vital Statistics, 2010 |
|---|-------------|---------------------------|---------------------------|---------------------------|---------------------------|
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                           |                           |                           |                           |
| Is the Data Provisional or Final?   |             |                           |                           | Final                     | Provisional               |
|   | <b>2012</b> | <b>2013</b>               | <b>2014</b>               | <b>2015</b>               | <b>2016</b>               |
| Annual Performance Objective  | 1           | 1                         | 1                         | 1                         | 1                         |

#### **Notes - 2011**

Source: MD Vital Statistics Administration Report, 2010; Data for 2011 not currently available

#### **Notes - 2010**

Source: MD Vital Statistics Administration Report, 2010

#### **Notes - 2009**

Source: MD Vital Statistics Administration Report, 2009

#### **a. Last Year's Accomplishments**

Injuries, including motor vehicle crashes continue to be the leading cause of death for Maryland children. In 2010, (the most recent year for which data is available from the Vital Statistics Administration), 12 Maryland children died as a result of a car crash and another 204 suffered nonfatal injuries requiring hospitalization. The death rate of Maryland Children aged 14 and younger due to motor vehicle crashes was 1.1 per 100,000 in 2010 as compared to 2.3 per 100,000 in 2008. Deaths due to motor vehicle crashes have been declining for this age group.

In FY 2011, the Title V MCH Program continued to provide support and technical assistance to State and local Child Fatality Review (CFR) teams, which are legislatively mandated to review child deaths in Maryland, including those caused by motor vehicle crashes. Each year, the Child Death Report prepared by the MCH epidemiologist for the State Child Fatality Review Team identifies trends in deaths due to motor vehicle crashes.

State activities directed at preventing deaths due to motor vehicle crashes largely fall outside of the purview of the MCH Program. Maryland has enacted several strict safety belt laws. As a result of aggressive enforcement of these laws, Maryland has a 94% seat belt usage rate, one of the highest on the east coast. Children and young people up to 16 years of age must be secured in seat belts or child safety seats, regardless of their seating positions and may not ride in an unenclosed cargo bed of a pick-up truck. Maryland law also strictly forbids driving while impaired by alcohol or other drugs and the minimum lawful drinking age is 21 years.

Maryland law requires that, "A person transporting a child under the age of 8 years in a motor vehicle shall secure a child in a safety seat in accordance with the child safety seat and vehicle manufacturers' instructions unless the child is 4 feet, 9 inches tall or taller; or weighs more than 65 pounds". Since the 1980's, the Maryland Kids in Safety Seats (KISS) Program has been the State's lead agency for promoting child passenger safety. KISS was housed in the Family Health

Administration's Center for Health Promotion and Education, Division of Injury Prevention and funded by the Maryland Department of Transportation in 2011. Its mission was to reduce the number of childhood injuries and deaths by educating the public (e.g., 1-800 helpline, media campaigns, and website) about child passenger safety including the correct use of child safety seats.

During National Child Passenger Safety Month in September 2011, jurisdictions throughout the State participated in child safety seat checks and community outreach and education activities. KISS continued to administer a loaner program that provided child safety restraints to over 800 low-income families in FY 2011. In addition, KISS facilitated or assisted with 17 national child passenger safety certification trainings to Marylanders including but not limited to health care/nursing personnel, fire and rescue workers, social services, foster care support staff, police cadets, law enforcement personnel, health department staff and auto dealership staff.

The Division of Injury Prevention in the Center for Health Promotion continued to provide mini-grants to local jurisdictions to address a broad range of injury prevention topics. Five of the 19 jurisdictions receiving funds in 2011 focused on improving child passenger safety by promoting car seat loaner programs and sponsoring educational events. The Division also supports the Partnership for a Safer Maryland which brings agencies together to focus on training and education to preventable injuries. Currently there is a sub-committee addressing MVA related issues, specifically distracted driving.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Conduct state and local child fatality review processes that include a review of deaths due to motor vehicle crashes  |                          |    |     | X  |
| 2. Enforce strict Maryland child safety seat, safety belt, and DUI laws  |                          |    |     | X  |
| 3. Enforce laws requiring children of certain weights and at certain ages to use child passenger safety seats  |                          |    |     | X  |
| 4. Educate the public about child safety seat laws and the correct use of child passenger safety seats. Administer the Kids in Safety Seats program that includes a free loaner program (Office of Health Promotion) |                          | X  |     |    |
| 5. Fund local injury prevention programs promoting motor vehicle safety (Family Health Administration)   |                          |    | X   |    |
| 6. Monitor data and trends. Publish an annual child fatality review report that includes data on deaths due to motor vehicle crashes   |                          |    |     | X  |
| 7. Collaborate with other agencies and coalitions (e.g. the Partnership for a Safer Maryland, and others) to reduce injuries   |                          |    |     | X  |
| 8.   |                          |    |     |    |
| 9.   |                          |    |     |    |
| 10.  |                          |    |     |    |

#### **b. Current Activities**

Ongoing activities are continuing in 2012. The MCH Epidemiologist is currently completing the 2012 Annual Child Death Report. Once again, the report identified injuries, including those due to motor vehicle accidents, as a leading cause of child deaths.

In November 2011, the Annual Maryland Child Fatality Review Team meeting included

presentations on distracted driver issues, a concern of injury specialists and legislators in Maryland. Last year, the Maryland Legislature banned the use of hand held cell phones as well as texting while driving.

The Department of Health and Mental Hygiene underwent a major reorganization this year. Effective July 1, 2012, the Center for Health Promotion which previously housed the Injury Prevention Unit was eliminated. These functions are now located within the Center for Injury and Sexual Assault Prevention within the Environmental Health Bureau.

### c. Plan for the Coming Year

In FY 2013, the State Child Fatality Review Team and the MCH Program will continue to partner with other DHMH and state agencies to reduce child deaths due to motor vehicle crashes.

MCH will continue to be represented on the Partnership for a Safer Maryland, in its efforts to advocate for injury and violence prevention. Addressing childhood deaths and injuries due to motor vehicle crashes is one important part of the Coalition's goals.

### **Performance Measure 11:** *The percent of mothers who breastfeed their infants at 6 months of age.*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>                                       | <b>2009</b>                                       | <b>2010</b>                                       | <b>2011</b>                                       |
|---|-------------|---|---|---|---|
| Annual Performance Objective  | 44          | 41  | 44  | 44  | 46  |
| Annual Indicator  | 43.0        | 45.5  | 43.3  | 45.5  | 45.2  |
| Numerator   | 33565       | 35516   | 33527   | 35516   | 34925   |
| Denominator   | 78057       | 78057   | 77430   | 78057   | 77268   |
| Data Source   |             | NIS, CDC, 2007 and 2007 Birth Data MD Vital Stat. | NIS, CDC, 2009 and 2007 Birth Data MD Vital Stat. | NIS, CDC, 2010 and 2007 Birth Data MD Vital Stat. | NIS, CDC, 2010 and 2007 Birth Data MD Vital Stat. |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |   |   |   |   |
| Is the Data Provisional or Final?   |             |   |   | Final   | Final   |
|   | <b>2012</b> | <b>2013</b>                                       | <b>2014</b>                                       | <b>2015</b>                                       | <b>2016</b>                                       |
| Annual Performance Objective  | 46          | 46  | 46  | 46  | 46  |

#### Notes - 2011

Source: Data on percentage of infants breastfeeding at 6 months is from the CDC National Immunization Survey 2011, based on births occurring in 2008.

This percentage was applied to the infant population (denominator) in Maryland in 2008 to produce an estimated numerator.

#### **Notes - 2010**

Source: Data on percentage of infants breastfeeding at 6 months is from the CDC National Immunization Survey 2010, based on births occurring in 2007.

This percentage was applied to the infant population (denominator) in Maryland in 2007 to produce an estimated numerator.

#### **Notes - 2009**

Source: Data on percentage of infants breastfeeding at 6 months is from the CDC National Immunization Survey 2009, based on births occurring in 2006.

This percentage was applied to the infant population (denominator) in Maryland in 2006 to produce an estimated numerator.

#### **a. Last Year's Accomplishments**

The 2011 Breastfeeding Report Card (Source: CDC National Immunization Survey of 2008 births) estimates that 78.5% of Maryland mothers initiated breastfeeding in 2008. However, fewer Maryland mother, 45.2%, continued to breastfeed their infants at 6 months of age ( only 10.5% exclusively breastfed).

Nationwide, the CDC reports continued racial disparity in breastfeeding rates. For 2007 births (latest data), nationally 58.1% of non-Hispanic Black, 76.2% of non-Hispanic white, and 80.6% of Hispanic mothers reported ever breastfeeding. Maryland PRAMS data for 2010 births similarly shows a racial disparity in breastfeeding rates in Maryland with 74% of non-Hispanic Black, 81% of non-Hispanic White, and 89% of Hispanic mothers reporting ever breastfeeding.

Maryland continued to have a Maryland Breastfeeding Coalition in 2011 that maintained a breastfeeding website at [www.marylandbreastfeedingcoalition.org](http://www.marylandbreastfeedingcoalition.org) containing resources for women, health professionals, and employers. The statewide Breastfeeding-Friendly Workplace Initiative, launched in February 2008, continued to recognize outstanding workplace lactation support programs by distributing "Maryland Breastfeeding-Friendly Workplace Awards." In 2011, at least 18 employer sites were designated as "Breastfeeding Friendly" Workplaces.

Breastfeeding promotion continued in Title V funded Improved Pregnancy Outcome (IPO) Programs in every jurisdiction in the State. Breastfeeding educational materials ("Breastfeeding Know-How" and "Benefits of Breastfeeding" brochures and "Maryland Breastfeeding Law" cards) were updated and continued to be provided free of charge to IPO programs and others. The Title V Program also continued to maintain a lactation support room for breastfeeding DHMH employees,

Lactation support in all Maryland birthing hospitals, as outlined in the Maryland Perinatal System Standards, was promoted through Title V involvement in the statewide Perinatal and Neonatal Learning Networks. In 2011, the Morbidity, Mortality, and Quality Review Committee began site visits to the level I and level II hospitals in the State to monitor compliance with the Maryland Perinatal System Standards, including the expectation of lactation support. Breastfeeding support materials were distributed to hospitals at every site visit.

The WIC Program continued to promote breastfeeding as the preferred method of infant feeding for all clients. WIC has a Breastfeeding Coordinator and all WIC staff have received training in advanced lactation support. WIC also continued its Peer Counseling Breastfeeding Support

Program in several Maryland counties.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Disseminate breastfeeding support materials and provide technical assistance for employers to promote breastfeeding support in the workplace, as now mandated by federal health care reform legislation |                          |    |     | X  |
| 2. Redesign the, "Breastfeeding-Friendly Workplace award," to recognize exemplary support programs and program maintained by small businesses (less than 50 employees)                                     |                          |    |     | X  |
| 3. Educate the public about the passage of, "right to breastfeed," legislation in Maryland   |                          |    | X   |    |
| 4. Fund and support breastfeeding promotion activities in local health departments   |                          |    |     | X  |
| 5. Educate health care providers about the benefits of breastfeeding and encourage health providers to promote breastfeeding   |                          |    | X   |    |
| 6. Maintain standards for lactation support in all Maryland's birthing hospitals   |                          |    |     | X  |
| 7. Update and maintain the Maryland breastfeeding website  |                          |    |     | X  |
| 8.   |                          |    |     |    |
| 9.   |                          |    |     |    |
| 10.  |                          |    |     |    |

**b. Current Activities**

In early FY 2012, the Title V program began collaborating with the MD Institute of Emergency Medical Services Systems (MIEMSS) to conduct site reviews of level III hospitals. Breastfeeding support is being reviewed at these site visits.

Maryland has 33 hospitals that offer maternal and newborn services. In FY 2012, DHMH formed a Work Group to review current breastfeeding policies in these hospitals and to develop a set of hospital breastfeeding policy recommendations. Both the Title V Director and the Medical Director for the State MCH Program participate on this Work Group which is being chaired by the WIC Program Director. Draft Work Group recommendations have been distributed broadly for comment and feedback. A final report and policy document will be issued with the next several months.

**c. Plan for the Coming Year**

During the coming year, the Title V Program plans to continue its ongoing activities that support breastfeeding as the norm for infant feeding in Maryland. Plans for FY 2013 include:

- To partner with the WIC Program and others to implement final hospital breastfeeding policy recommendations in Maryland;
- To outreach to businesses in the State, including State agencies, with resource materials and technical assistance to help them meet the federal Health Care Reform requirements to support lactating women in the workplace;
- To showcase outstanding workplace lactation support programs by recognizing them with the Maryland Breastfeeding-Friendly Workplace Award;
- To expand awareness in the state of the Maryland law protecting the right to breastfeed;
- To provide outreach and technical assistance to local health departments and other State

agencies to implement breastfeeding promotion activities appropriate to their area of responsibility;

- To continue site visits to level I and level II hospitals, reviewing compliance with the Maryland Perinatal System Standards, including the expectation of lactation support;
- To continue to educate health care providers about the benefits of breastfeeding and encourage their promotion of breastfeeding;
- To expand community outreach activities to increase the number of Maryland mothers, of all racial and ethnic groups, who not only initiate breastfeeding but continue breastfeeding for at least 6 months; and.
- To continue to identify funding sources to address breastfeeding promotion activities.

**Performance Measure 12:** *Percentage of newborns who have been screened for hearing before hospital discharge.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>     | <b>2009</b>     | <b>2010</b>                   | <b>2011</b>                   |
|---|-------------|-----------------|-----------------|-------------------------------|-------------------------------|
| Annual Performance Objective  | 90          | 90              | 98              | 100                           | 100                           |
| Annual Indicator  | 92.5        | 98.8            | 98.7            | 98.4                          | 98.9                          |
| Numerator   | 68622       | 74276           | 70984           | 69637                         | 69592                         |
| Denominator   | 74196       | 75210           | 71917           | 70782                         | 70338                         |
| Data Source   |             | State IH System | State IH System | State IH System (Oz Database) | State IH System (Oz Database) |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                 |                 |                               |                               |
| Is the Data Provisional or Final?   |             |                 |                 | Final                         | Provisional                   |
|   | <b>2012</b> | <b>2013</b>     | <b>2014</b>     | <b>2015</b>                   | <b>2016</b>                   |
| Annual Performance Objective  | 100         | 100             | 100             | 100                           | 100                           |

**Notes - 2011**

Number of occurrent births is from the Maryland Infant Hearing Program's OZ eSP database. The number of occurrent births is 70,733, however the number of births requiring a screen (excludes deceased, refused, hospice, etc.) is used as the denominator (70,388). This data is for the calendar year 2011.

**Notes - 2010**

Number of occurrent births is from the Maryland Infant Hearing Program's OZ eSP database. Calendar year 2010 marks the first full year that this database was fully functional for the entire reporting period.

**Notes - 2009**

Number of occurrent births is from MD Vital Statistics and is only provisional at this time. The screening data is primarily from the old state IH system because the new OZ eSP system was not in place for the full year.

While we would like to maintain our progress in screening an increasing percentage of babies before hospital discharge, our historical struggles with databases and providers, make us wary of setting 100% as the measure for satisfactory performance. It may not be realistic.

#### **a. Last Year's Accomplishments**

The calendar year 2011 Maryland hospital birth population included 70,388 newborns who required hearing screens (birth population less home/maternity center births, infant deaths or hospice releases, infants transferred out of state, and infants whose parent refused screening.) The vast majority (69,592) of those babies underwent newborn hearing screening as inpatients and an additional 540 were tested as outpatients. This translates to a 99.7% screening rate for Maryland. There were 67,114 infants who passed the birth screen and 2,478 who failed, giving Maryland a 96.4% pass rate.

A total of 2,135 of the 3,274 babies who missed or failed their birth screening returned for outpatient screening and 379 had a diagnostic evaluation in place of a second screening. This total (2,514) equals a 76.8% return rate and shows significant improvement as compared to previous years. Of the remaining 760 babies, 136 were not Maryland residents or moved out of state following their inpatient screen, and/or their follow-up was transferred to their state of residence. 33 babies expired following the missed or initial screen, 3 refused further testing and the remaining 588 were lost to follow-up.

Of the 2,227 infants who returned for follow-up, 1941 passed the second screen and 286 had a normal diagnostic evaluation. This translates to an 88.6% rescreen pass rate. Of the 193 who failed the second screen, 63 were found to have some type or degree of hearing loss and 33 had incomplete hearing evaluations. Of the 379 who skipped the second screen and went directly to diagnostic evaluation, 47 were found to have some type or degree of hearing loss and 46 had incomplete hearing evaluations. During CY11, 121 infants were documented as having hearing loss and of that number, 92 infants were documented as having been referred for early intervention services. Follow-up efforts were negatively impacted by a vacancy for one of two follow-up coordinator positions during much of FY11.

The Infant Hearing Program (IHP) fulfilled the vacancy for a program director and for the voluntary position of American Academy of Pediatrics (AAP) EHDI (Early Hearing Detection and Intervention) Chapter Champion. In early FY12, the Chapter Champion conducted a survey of area physicians to gather information about educational needs and preferences with regard to the MD EHDI program and used the results to plan education and outreach efforts within this community. The IHP continued collaboration with OZ Systems to enhance the eSP™ database. Database enhancements included the design and build of an Early Intervention module and a de-duplication tool. The IHP collaborated with the Maryland State Department of Education to establish a data matching system between the MSDE database and the IHP database in order to improve our ability to evaluate outcomes of infants referred for Early Intervention. The ability to generate hospital compliance reports on demand was created. The database system also automatically adds the NICU risk factor when a patient's nursery status is NICU for greater than 5 days, and improvements in the system now allow risk factor letters to be generated at the appropriate time. The IHP collaborated with the Birth Defects Registry Information System (BDRIS) to confirm and/or obtain certain risk factor data through that program. The IHP also collaborated with the Maryland Vital Statistics Administration (VSA) to confirm reports of infant deaths and to ensure that the IHP receives record of all live occurrent births in hospitals as well as out of hospital births.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Support hearing screening for all Maryland newborns. |                          |    | X   |    |

|   |  |   |   |   |
|---|--|---|---|---|
| 2. Provide tracking and follow-up on all screening referrals and not tested infants to confirm hearing status.  |  | X | X |   |
| 3. Education materials regarding hearing screening for parents, families and providers developed and available  |  | X | X | X |
| 4. Education materials developed and available for parents regarding hearing evaluation and developmental milestones in multiple languages for provider use.          |  | X | X | X |
| 5. Enhance the program website to include educational brochures, links to web-based OZ eSP reporting system, and reporting forms in downloadable format for providers |  | X | X | X |
| 6. Continue training in an on-going manner for birthing facilities and audiologists/other providers entering patient data in the web-based OZ eSP reporting system.   |  | X | X | X |
| 7. Birthing facilities provided with site evaluations.  |  | X | X | X |
| 8. Continue the enhancement of the eSP database to add additional features  |  | X | X | X |
| 9.  |  |   |   |   |
| 10.   |  |   |   |   |

#### **b. Current Activities**

Database enhancements continue this year. The development of the automatic data downloading from the birth hospitals' databases into the eSP™ database is in process. This will allow the IHP to obtain complete and accurate data and it will reduce the documentation burden for hospital staff. The eSP™ database was also modified to capture birth defects data.

The Hearing Advisory Council held its 6th Maryland EHDl Stakeholders Meeting in August, 2011 and the keynote address was entitled, "Fostering EHDl in the Medical Home." The 7th Stakeholders Meeting was held in May, 2012 and the theme was "Partnering with Families." Topics included children with hearing loss and co-existing disabilities, providing linguistically competent EHDl services to Latino/Hispanic families, and presentation of the new Maryland "Parent Connections" mentor program for families of children newly identified with hearing loss.

The MD AAP EHDl Chapter Champion, Susan Panny, M.D. is engaged in efforts to educate physicians and to promote reporting of hearing test results into the MD EHDl database; for example she conducted an education and outreach presentation about MD EHDl to the Bradley Society that included a live demonstration and on-the-spot enrollment. Finally, The second follow-up coordinator position is currently vacant after being filled for approximately one month during FY12.

#### **c. Plan for the Coming Year**

It is anticipated that a new follow up coordinator will be hired in early FY13. The Parent Connections program is expected to expand as outreach to audiology practices continues. Since the official launching of the Parent Connections program on May 17, 2012, there have been 3 confirmed matches. A parent packet is being developed which will include information that will assist parents of children who are newly identified with hearing loss. Referral protocols have been established for connecting families to the program. The MD EHDl program audiologist and the parent liaison to the Parent Connections Program are conducting site visits to area audiologists and hospitals to promote the parent mentor program.

During FY13 the IHP will provide hearing screening equipment and training to local health departments and birthing centers. Outreach to the midwife community will continue and this will be combined with outreach and education regarding the upcoming implementation of newborn screening for Critical Congenital Heart Disease. A site visit will be conducted with the other



birthing center in Maryland and communication with midwives performing home births is planned.

The MD EHDI program continues to work with the state EHDI AAP Chapter Champion to increase provider participation within the MD EHDI program. Outreach efforts include the development of an MDAAP EHDI webpage to market usefulness of the MD EHDI database, increasing pediatricians' knowledge about newborn hearing screening/follow up and the EHDI system in Maryland through a web page featuring recorded webinars, useful links, and downloadable print materials. The Chapter Champion applied for and received a \$2500 education and training grant from the AAP to support some of these activities.

Maryland will be first time participants in the NICHQ Learning Collaborative during FY 13. Participation is a requirement of a HRSA grant entitled, "Reducing Follow-up after Failure to Pass Newborn Hearing Screening.". There will be five participants -- the Infant Hearing Program chief and audiologist, the OGCSHCN Systems Development Chief, a family resources coordinator for the state school for the deaf, and a parent of a child who is deaf or hard of hearing.

IHP database enhancements will continue with CDC funding to include full implementation of the auto-population data linkage for patient records in all Maryland birth hospitals.

### **Performance Measure 13: *Percent of children without health insurance.***

#### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>                        | <b>2009</b>                        | <b>2010</b>                                 | <b>2011</b>                                 |
|---|-------------|------------------------------------|------------------------------------|---|---|
| Annual Performance Objective  | 9.6         | 12.1                               | 10                                 | 11  | 9   |
| Annual Indicator  | 12.0        | 10.0                               | 10.0                               | 9.2   | 9.2   |
| Numerator   | 163264      | 136300                             | 136300                             | 125000                                      | 125000                                      |
| Denominator   | 1360531     | 1363004                            | 1363004                            | 1355000                                     | 1355000                                     |
| Data Source   |             | U.S. Census Bureau, CPS, 2008-2009 | U.S. Census Bureau, CPS, 2008-2009 | U.S. Census Bureau, CPS, 2010 ASEC for 2011 | U.S. Census Bureau, CPS, 2010 ASEC for 2011 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                                    |                                    |   |   |
| Is the Data Provisional or Final?   |             |                                    |                                    | Final                                       | Provisional                                 |
|   | <b>2012</b> | <b>2013</b>                        | <b>2014</b>                        | <b>2015</b>                                 | <b>2016</b>                                 |
| Annual Performance Objective  | 9           | 9                                  | 9                                  | 8   | 8   |

#### **Notes - 2011**

Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement, 2010

Children defined as age 18 and under.

2011 data not available

#### **Notes - 2010**

Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement, 2010

Children defined as age 18 and under.

#### **Notes - 2009**

Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement, 2008-2009 (2-year average of data collected in 2008 and 2009). Children defined as age 18 and under.

#### **a. Last Year's Accomplishments**

In 2010, an estimated 7% of Maryland's children aged 0-18 were uninsured. Medicaid and MCHP are partially credited with a Maryland trend towards decreasing numbers of uninsured children. Among racial/ethnic groups, the uninsured rate is highest for Hispanics (19%). Children living in poor or near poor families (< 200% of the poverty level) are four to five times more likely to be uninsured than children living in wealthier families (> 400% of the poverty level).

The Medical Assistance and the Maryland Children's Health Insurance (MCHP) Programs continued to provide health insurance coverage for low income children. MCHP, which is administered by the Medicaid Program, provided access to health insurance coverage for significant numbers of uninsured Maryland children in families with incomes up to 300% of the poverty level. MCHP Premium serves children in families with incomes between 200% and 300% of the federal poverty level. Enrolled families pay a monthly contribution. During 2011, enrollment in MCHP exceeded 138,000 while Medicaid provided coverage to over 492,000 children and youth ages 0-19.

The Children's Medical Services Program within the OGCSHCN continued to provide coverage for specialty care for uninsured and underinsured CSHCN in family incomes below 200% of the federal poverty level. Since Medical Assistance also covers this same income group, most of the children served are undocumented.

The MCH Hotline (1-800-456-8900) refers families to local health departments to receive assistance in determining their eligibility for Medicaid and MCHP programs. The Hotline received more than 8,400 calls requesting information about eligibility for Medicaid services in 2011. During Child Health Month and other special observances, the CMCH Outreach Coordinator works closely with local health agencies to distribute pamphlets and other materials that promote Medicaid and MCHP. Resource guides, brochures and fact sheets were distributed by CMCH at health fairs and community events.

Governor O'Malley created the Maryland Health Care Reform Coordinating Council through an Executive Order in 2010 to advise the administration on policies and procedures to implement federal health reform. Lieutenant Governor Anthony Brown and Department of Health and Mental Hygiene Secretary John Colmers co-chaired the Council. The Council released its final report in January 2011.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Refer families to Medicaid and medical services through the MCH hotline  |                          | X  |     |    |
| 2. Provide health insurance coverage for eligible low income children in families with low incomes to 250% of FPL through Medicaid and MCHP   |                          | X  |     |    |
| 3. Provide coverage for eligible CYSHCN through the Office of Genetics and Children with Special Health Care Needs  |                          | X  |     |    |
| 4. Provide outreach to enroll children into Medicaid and MCHP. Disseminate resource information including source of financial assistance for health care at health/community health fairs and other outreach events (MCH staff in local health departments) |                          | X  |     |    |
| 5. Assess health needs and issues confronting uninsured children and families including geographic and racial/ ethnic disparities   |                          |    |     | X  |
| 6.  |                          |    |     |    |
| 7.  |                          |    |     |    |
| 8.  |                          |    |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

**b. Current Activities**

In FY 2012, State and local MCH programs have continued to support the Medicaid Program in enrolling eligible children and adolescents. Outreach strategies include distributing MCHP/Medicaid eligibility information to schools, licensed day care centers, Head Start programs, and at community events and health fairs. As funding allows, periodic media campaigns are used to promote the MCH Information and Referral Hotline. The MCH Hotline is continuing to refer pregnant women and families to local health departments and other program sites that determine eligibility for Medical Assistance Programs.

Legislation passed during the 2011 Maryland Legislative Session requires the Medical Assistance Program to provide family planning services to all women whose family income is at or below 200% of federal poverty guidelines regardless of how recently a woman has delivered a child. The Program began enrolling women on January 1, 2012. To date, approximately 2,000 women have enrolled. The Title X and Title V Programs are assisting with program outreach and have developed a media campaign to promote the expansion program. Medicaid savings from a reduction in unintended pregnancies and births are anticipated.

**c. Plan for the Coming Year**

Ongoing activities will continue in 2013.

Reforming the health care system to reduce the numbers of uninsured in Maryland continues to be a priority of the Governor, Lieutenant Governor and Health Secretary Sharfstein. On April 12, 2011 Governor O'Malley signed into law the Maryland Health Benefit Exchange Act of 2011 to develop Maryland's approach to meeting the Affordable Care Act requirement for states to either establish and operate a Health Insurance Exchange by 2014 or participate in the federal Exchange. Maryland has chosen to operate its own Exchange, rather than join a multi-state Exchange or default to a federal Exchange. The Exchange will allow Marylanders to compare rates, benefits, and quality among plans to help individuals and small employers find an insurance product that best suits their needs. The State applied for and was awarded an Exchange Planning and Establishment Grant. Work on the Exchange will continue in 2013.

**Performance Measure 14:** *Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>               | <b>2009</b>               | <b>2010</b>               | <b>2011</b>               |
|---|-------------|---------------------------|---------------------------|---------------------------|---------------------------|
| Annual Performance Objective  | 32.5        | 32.5                      | 32                        | 33                        | 32                        |
| Annual Indicator  | 33.0        | 33.1                      | 33.2                      | 32.2                      | 32.3                      |
| Numerator   | 11881       | 14326                     | 16302                     | 20593                     | 21001                     |
| Denominator   | 36002       | 43317                     | 49065                     | 63951                     | 65020                     |
| Data Source   |             | WIC Program Data for 2008 | WIC Program Data for 2009 | WIC Program Data for 2010 | WIC Program Data for 2011 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |                           |                           |                           |                           |
| Is the Data Provisional or Final?   |             |                           |                           | Final                     | Final                     |
|   | <b>2012</b> | <b>2013</b>               | <b>2014</b>               | <b>2015</b>               | <b>2016</b>               |
| Annual Performance Objective  | 31          | 31                        | 31                        | 31                        | 31                        |

**Notes - 2011**

Source: Maryland WIC Program data; Maryland WIC estimates for 2011 based on enrollment and BMI analysis for the period, January-December 2011.

**Notes - 2010**

Source: Maryland WIC Program data; Maryland WIC estimates for 2010 based on enrollment and BMI analysis for the period, July-December 2010.

**Notes - 2009**

Source: Maryland WIC Program data; Maryland WIC estimates for 2009 based on enrollment and BMI analysis for the period, July-December 2009.

**a. Last Year's Accomplishments**

WIC program data continues to a primary source for overweight and obesity data for children younger than five years of age. WIC Program data for 2011 indicates that one in three WIC enrollees, ages two to five, was overweight or obese. In 2011, the prevalence of obesity in Hispanic children (42.5%) enrolled in WIC was higher than that for White (30%) and African American (27%) children.

Surveillance data on overweight and obesity among Maryland children and adolescents is limited, but improving. Data sources continue to include the Maryland Youth Risk Behavior Survey (2011 is the latest year), the Maryland Youth Tobacco survey, BMI data collected by the WIC Program through the Maryland Pediatric Nutrition Surveillance System, and Medicaid data collected from chart reviews. The most recent data from the National Survey of Children's Health for the year 2007 provides statewide estimates of the percentage of children, ages 10-17, who are overweight or obese. An estimated 13.3% were obese and another 16.6% were at risk for being overweight.

African American (42%) and Hispanic (32%) children were more likely than White (24%) children to be classified as overweight/obese. The 2011 YRBS report similarly estimates that one in four Maryland youth were overweight or obese in 2011 (defined as greater than the 85th percentile for body mass index).

The reduction of childhood overweight/obesity has been identified as a priority issue in recent Title V MCH needs assessments and in the Maryland State Health Improvement Plan (SHIP) completed in 2011. The SHIP's goal is to reduce the percentage of obese children in the State from a baseline of 11.9% in 2010 to 11.3% in 2014.

The Office of Chronic Disease Prevention (OCDP) had lead responsibility for addressing overweight/obesity in Maryland in 2011. A full time childhood wellness coordinator manages programmatic activities. CMCH continued to collaborate with OCDP to address childhood obesity through strategic planning, surveillance, provider education, research translation, and public awareness initiatives. The State Advisory Council on Heart Disease and Stroke with state support from ODCP continued to maintain a Childhood Obesity subcommittee. This subcommittee brings together statewide stakeholders to provide strategic direction and oversight to childhood obesity initiatives.

In 2011, Dr. Cheryl DePinto continued to lead childhood obesity prevention activities for CMCH and served on the American Academy of Pediatrics, Maryland Chapter, Childhood Obesity Committee, which partners with CMCH and the OCDP on obesity prevention strategies, outreach, and education. Additionally, she served as the liaison to OCDP in implementing the Maryland Nutrition and Physical Activity Plan.

Last year, DHMH launched ChopChop Maryland magazine to engage families in planning, cooking, and dining together to protect against childhood obesity. ChopChop Maryland uses social media strategies including Facebook and text messaging to provide families monthly newsletters highlighting easy, healthy recipes based upon seasonal Maryland ingredients. DHMH also encouraged fresh fruit and vegetable consumption through the Fruits and Veggies More Matters mass transit marketing campaign in the Summer of 2011 to correspond with the farmers market season.

In November 2011, DHMH worked with the University of Maryland Baltimore to co-sponsor a two day Summit on Childhood Obesity to address the growing issue of childhood obesity in Maryland. Over 400 stakeholders from across the state attended and several national experts participated in the Summit including Dr. William Dietz of the CDC and Dr. John Ruffin of NIH. Follow-up activities include the establishment of the Institute for a Healthiest Maryland, which engages higher education experts from Maryland's colleges and universities to provide evidence-based resources coordinate training and technical assistance, and support communication and best practice dissemination efforts by maintaining an interactive website and email network.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Collaborate with the Office of Chronic Disease Prevention (OCDP), WIC, and others to plan and implement strategies to reduce childhood overweight and obesity |                          |    |     | X  |
| 2. Implement child and adolescent health components of the state's most recent Physical Activity Plan  |                          |    |     | X  |
| 3. Work with the MD AAP, Medicaid, and others to improve surveillance  |                          |    |     | X  |

|  |  |  |   |   |
|--|--|--|---|---|
| 4. Promote awareness of childhood overweight and obesity among health providers, families, and the general public through presentatinos, funding of pilot programs and conducting education sessions |  |  | X |   |
| 5. Support implementation of referral networks and other services for children who are overweight or obese   |  |  |   | X |
| 6. Collaborative efforts with the OCDP to develop policy recommendations for reimbursement for obesity risk assessment, prevention, and treatment  |  |  |   | X |
| 7.   |  |  |   |   |
| 8.   |  |  |   |   |
| 9.   |  |  |   |   |
| 10.  |  |  |   |   |

#### **b. Current Activities**

Several activities have focused on improving early childhood wellness. The School Health Interdisciplinary Program (SHIP) is an annual continuing education opportunity that provides intensive training on all components of coordinated school health. In July 2012, an early childhood obesity prevention training will be provided through a SHIP session on Let's Move child care. This year, Title V ECCS funds were used to support a pilot demonstration project to improve healthy eating and physical activity habits among young African American children enrolled in child care and their parents in a rural Maryland community. Title V is now exploring further expansion of the program.

A recent Johns Hopkins University study found that more than a third of Baltimore neighborhoods are located in food deserts where residents don't have ready access to healthy foods. In February 2012, DHMH became a member of the Maryland Fresh Food Retail Task Force to help to identify opportunities for retailing of healthy foods. The Food Trust facilitates this task force, which brings together multiple sectors and organizations throughout the state to address food deserts where children do not have access to healthy foods.

#### **c. Plan for the Coming Year**

During 2013, Maryland will continue to promote healthier environments for preschool and school age children through collaboration with the Maryland State Department of Education regarding child care and school wellness initiatives by participating in the Health and Physical Education Advisory Committee and the Maryland State School Health Council. Strengthening childcare licensing standards to align with Caring for our Children (CFOC): National Health & Safety Performance Standards for Early Care and Education Programs (3rd Ed.) specific to nutrition, physical activity and screen time standards is a goal for 2013.

Additionally, a Health and Wellness Designation for early care and education programs with enhanced nutrition, physical activity, and screen time practices will be developed by DHMH and MSDE as part of Tiered Quality Rating and Improvement System (Maryland EXCELS) implementation.

The Title V Program and the OCDP will continue to partner with the Maryland Chapter of the American Academy of Pediatrics to improve child care wellness, support local school wellness policy implementation and monitoring, and identify best practices for children who are overweight/obese. Many MD-AAP members provide leadership for childhood obesity prevention by supporting both community and state-level strategies that improve physical activity and nutrition opportunities.

**Performance Measure 15:** *Percentage of women who smoke in the last three months of pregnancy.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>   | <b>2009</b>   | <b>2010</b>    | <b>2011</b>    |
|---|-------------|---------------|---------------|----------------|----------------|
| Annual Performance Objective  | 10.7        | 7.6           | 9             | 11             | 9              |
| Annual Indicator  | 9.3         | 10.9          | 9.1           | 9.3            | 9.3            |
| Numerator   | 6160        | 7357          | 6051          | 6115           | 6115           |
| Denominator   | 66425       | 67625         | 66567         | 65950          | 65950          |
| Data Source   |             | MD PRAMS 2008 | MD PRAMS 2009 | MD PRAMS, 2010 | MD PRAMS, 2010 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |               |               |                |                |
| Is the Data Provisional or Final?   |             |               |               | Final          | Provisional    |
|   | <b>2012</b> | <b>2013</b>   | <b>2014</b>   | <b>2015</b>    | <b>2016</b>    |
| Annual Performance Objective  | 8.5         | 8.5           | 8.5           | 8.5            | 8.5            |

**Notes - 2011**

Source: Maryland PRAMS 2010; Data for 2011 currently unavailable.

**Notes - 2010**

Source: Maryland PRAMS 2010

**Notes - 2009**

Source: Maryland PRAMS 2009

**a. Last Year's Accomplishments**

Data from the 2010 Maryland Pregnancy Risk Assessment Monitoring System (PRAMS) survey indicates that 9% of women surveyed reported smoking during the last 3 months of pregnancy. Smoking was most prevalent among White non-Hispanic (13%) and younger mothers (24%). Among mothers over the age of 19, those with more than a 12th grade education were much less likely to smoke (3%) than those with a 12th grade education or less (16%). Local health departments, particularly in rural areas of the State, have anecdotally continue to note increasing rates of smoking among pregnant women.

In 2011, the Maryland Center for Health Promotion was the lead agency responsible for smoking cessation activities in DHMH. This Center administers three smoking cessation programs that include a focus on pregnant women: (1) the Smoking Cessation in Pregnancy (SCIP) Program; (2) a statewide toll-free telephone quitline that delivers cessation counseling services without charge (Quitline); and (3) in-person smoking cessation counseling conducted through local health departments outside the SCIP program (LHD-C Program).

SCIP, the Smoking Cessation in Pregnancy Program, is a multi-component program that trains local health department and Medicaid managed care staff to facilitate smoking cessation among pregnant women and women considering pregnancy. Female smokers meet with public health nurses who counsel them to quit or reduce tobacco use. Along with one-on-one counseling, participants receive self-help materials in the form of a manual and a "Quit Kit."

A statewide Quitline (1-800-QUIT-NOW) continued to provide cessation counseling by 'Free & Clear' tailored to the individual needs of callers, including pregnant women. During Fiscal Year 2011, the Quitline served 51 pregnant women, 57 women planning to become pregnant during the next 3 months, and 10 breastfeeding women..

During FY 2011, local health departments provided smoking cessation services to 367 pregnant women. These services included promoting smoking cessation during pregnancy as a part of preconception health counseling during family planning clinic visits. Some clinics supplied nicotine patches and/or Zyban to clients. Educational materials promoting smoking cessation were also offered during home visits and at health fairs and other educational events. Local health departments continued to partner with groups such as the March of Dimes to educate pregnant women about the health risks linked to smoking during pregnancy.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Monitor trends in smoking rates during pregnancy using several data sources including PRAMS and birth records   |                          |    |     | X  |
| 2. Promote smoking cessation during preconception health counseling in family planning clinics. This will be done during local health department prenatal care clinic visits, and during prenatal and postpartum home visits |                          | X  |     |    |
| 3. Refer women of child bearing age who smoke to cessation program including Smoking Cessation in Pregnancy (SCIP) administered by the Office of Health Promotion  |                          | X  |     |    |
| 4. Promote smoking cessation in schools  |                          |    | X   |    |
| 5. Enforce MD laws enacted to eliminate smoking in schools   |                          |    |     | X  |
| 6. Support enforcement of Maryland's statewide Clean Indoor Air legislation that prohibits smoking in all indoor work-sites including restaurants and bars   |                          |    |     | X  |
| 7.   |                          |    |     |    |
| 8.   |                          |    |     |    |
| 9.   |                          |    |     |    |
| 10.  |                          |    |     |    |

#### **b. Current Activities**

The Center for Health Promotion was eliminated under the recent DHMH reorganization. Tobacco prevention activities are now housed under the Center for Tobacco Prevention and Control within the newly created Cancer and Chronic Disease Bureau.

This year, the Maryland Tobacco Control Program provided a specialized training to providers on assisting pregnant woman with cessation counseling for the Administrative Care Coordination Unit Programs in local health departments, developed a flyer specific to pregnant women to promote the Quitline, and began reporting the number of pregnant callers to the Quitline to StateStat. StateStat is a performance-measurement and management tool implemented by Maryland's Governor to measure and ensure program accountability and efficiency.

CMCH continues to collaborate with multiple intra and inter-agency groups including the Maryland Tobacco Program and local health departments to promote strategies to reduce smoking during pregnancy. The Maryland PRAMS Survey annually publishes data on the smoking behaviors of women during and following pregnancy.



**c. Plan for the Coming Year**

In 2013, ongoing activities will continue. In addition, Maryland will begin full implementation of the MIECHV Home Visiting Program in 2013. As part of the benchmarking process, data will be collected and tracked on the percent of mothers screened positive for tobacco use who are referred to cessation programs.

**Performance Measure 16:** *The rate (per 100,000) of suicide deaths among youths aged 15 through 19.*

**Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b>  | <b>2007</b> | <b>2008</b>                            | <b>2009</b>               | <b>2010</b>               | <b>2011</b>               |
|---|-------------|--|---------------------------|---------------------------|---------------------------|
| Annual Performance Objective  | 4.6         | 4.1                                    | 6.6                       | 5                         | 7                         |
| Annual Indicator  | 6.6         | 4.7                                    | 7.0                       | 4.9                       | 4.9                       |
| Numerator   | 27          | 19                                     | 28                        | 20                        | 20                        |
| Denominator   | 408340      | 407227                                 | 401581                    | 406241                    | 406241                    |
| Data Source   |             | MD Vital Statistics Annual Report 2008 | MD Vital Statistics, 2009 | MD Vital Statistics, 2010 | MD Vital Statistics, 2010 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |  |                           |                           |                           |
| Is the Data Provisional or Final?   |             |  |                           | Final                     | Provisional               |
|   | <b>2012</b> | <b>2013</b>                            | <b>2014</b>               | <b>2015</b>               | <b>2016</b>               |
| Annual Performance Objective  | 4.5         | 4.5                                    | 4.5                       | 4.5                       | 4.5                       |

**Notes - 2011**

Source: MD Vital Statistics Annual Report, 2010; 2011 data is currently unavailable.

**Notes - 2010**

Source: MD Vital Statistics Annual Report, 2010

**Notes - 2009**

Source: MD Vital Statistics Annual Report, 2009

**a. Last Year's Accomplishments**

Suicide and homicide are leading causes of deaths among adolescents in Maryland. The rate (per 100,000 population) of suicide deaths among youths aged 15 through 19 was 4.9 in 2010. This represented a decrease over the 2009 rate of 7.0 (per 100,000 population). The actual numbers of suicides in this age range decreased from 28 in 2009 to 20 in 2010. The suicide rate

remained highest for White male teens in 2010.

Youth Risk Behavior Survey (YRBS) data for 2011 (the most recent available), helped to define the magnitude of depression and suicide among adolescents in Maryland. These data indicated that:

- One in four high school students reported feeling sad or hopeless, a proxy measure for depression. Rates were higher for females (31%) than males (19%). Overall:
- 16.2% reported seriously considering suicide, while 12.6% indicated making a suicide plan.
- 10.9% reported attempting suicide; females (11%) more only slightly more likely than males (10%) to report an attempt.
- 5.2% reported requiring medical attention following a suicide attempt.

The Maryland Mental Hygiene Administration (MHA) has lead responsibility for administering programs to prevent adolescent suicide among youth and young adults ages 15-24. Maryland is nationally recognized as a leader in reducing adolescent suicide rates among this age group. For the past 16 years, October has been proclaimed as Youth Suicide Prevention Month in Maryland and MHA sponsors an annual conference on suicide prevention. Funds are also awarded to local school districts to sponsor educational events. A full time Youth Suicide Prevention Coordinator supports these activities.

Maryland was the first State in the nation to offer a toll free decentralized Youth Crisis hotline service to address the needs of troubled youth. The 24-hour toll free Youth Crisis Hotline (1-800-422-0008) is staffed by trained counselors and uses a decentralized system which enables the counselor to access or refer the youth to local agencies for assistance. Throughout its 19 year history, the hotline has been very successful in intervening with youth considering suicide.

The Governor's Commission on Suicide Prevention was created by Executive Order in 2009. The Commission's purpose is to decrease suicide across the life span in Maryland by increasing citizen awareness, use of best practices, training and techniques, and access to life saving resources. The Commission was charged with developing a strategic plan to target suicide prevention, intervention and post-vention. The Title V Program's Child Fatality Review Coordinator continued to represent DHMH on the Commission in 2011.

Youth suicide prevention activities were also supported with a grant from the Garrett Lee Smith Foundation in 2011. These funds were awarded to local jurisdictions to support work that focuses on reaching young people through schools and community based projects, particularly in high risk areas. The Johns Hopkins University is the grant manager.

MCH Program activities continued to focus on child fatality review (CFR) processes to prevent child deaths, data collection and analysis of suicide in annual CFR reports, and education and training around suicide prevention.

**Table 4a, National Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Conduct state and local level child fatality review processes that include suicide prevention   |                          |    |     | X  |
| 2. Support and participate in planning for the annual statewide youth suicide prevention conference  |                          |    |     | X  |
| 3. Work with the Mental Hygiene Administration's Youth Suicide Prevention Program to implement youth focused components of the State's suicide prevention plan including promotion of school based initiatives |                          |    |     | X  |

|  |  |   |  |   |
|--|--|---|--|---|
| 4. Promote the use of the statewide Youth Crisis Hotline   |  | X |  |   |
| 5. Monitor data on youth suicide and related factors   |  |   |  | X |
| 6. Participate in the grant review and award processes for the Garrett Lee Smith youth suicide prevention grant      |  |   |  | X |
| 7. Represent DHMH on the Governor's Commission on Suicide Prevention   |  |   |  | X |
| 8. Collaborate with other stakeholders to promote positive youth development through initiatives such as Ready by 21 |  |   |  | X |
| 9.   |  |   |  |   |
| 10.  |  |   |  |   |

#### **b. Current Activities**

Planning is proceeding on the 2012 Annual Suicide Prevention Conference. The Coordinator of the State Child Fatality Review Team continues as the DHMH/CMCH Title V representative on the planning committee. The next conference is scheduled for October 5, 2012. Title V funds are used to support this conference.

The Governor's Commission on Suicide Prevention is close to finalizing a statewide strategic plan to address suicide prevention. Youth suicide prevention is a large focus of the plan.

#### **c. Plan for the Coming Year**

The Mental Hygiene Administration, in collaboration with the Governor's Commission and CMCH, will continue to plan and implement the annual statewide suicide prevention conference. Title V funds will continue to be used to help in underwriting conference costs. The Mental Hygiene Administration will continue to administer and support a statewide Youth Crisis Hotline. There is also a plan to implement periodic media campaigns, and school based youth suicide prevention programs.

Title V will continue to provide lead staff support for the State Child Fatality Review Team as well as work in tandem with local teams in every jurisdiction. Child fatality review team processes include working to prevent teen deaths due to suicide. Members of the State and local Child Fatality Review Teams, as well as others, will continue to be encouraged to attend the annual suicide prevention conference to build skills in addressing cases of child and adolescent suicide.

The Title V supported Coordinator of the State Child Fatality Review Team will continue to serve as the DHMH representative on the Governor's Commission on Suicide Prevention. The Commission was established in 2009 to bring partners together to impact policy on suicide prevention. The Commission will work on implementation of the Suicide Prevention Plan to be completed in 2012.

Finally, the MCH Program will continue to review vital statistics data, YRBS results and data from other sources to gain a better picture of the magnitude of youth suicide and related factors (e.g., depression) in Maryland.

**Performance Measure 17:** *Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.*

#### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance                           | 89.6        | 89.7        | 89.8        | 92          | 92          |

|   |             |   |   |   |  |
|---|-------------|---|---|---|--|
| Objective   |             |   |   |   |  |
| Annual Indicator  | 89.3        | 89.4  | 90.6  | 91.2  | 91.2                                       |
| Numerator   | 1138        | 1156  | 1102  | 1031  | 1031                                       |
| Denominator   | 1275        | 1293  | 1217  | 1130  | 1130                                       |
| Data Source   |             | MD DHMH,<br>Vital<br>Statistics<br>Admin 2008 | MD DHMH,<br>Vital<br>Statistics<br>Admin 2009 | MD DHMH,<br>Vital<br>Statistics<br>Admin 2010 | MD DHMH,<br>Vital Statistics<br>Admin 2010 |
| Check this box if you cannot report the numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |   |   |   |  |
| Is the Data Provisional or Final?   |             |   |   | Final   | Provisional                                |
|   | <b>2012</b> | <b>2013</b>                                   | <b>2014</b>                                   | <b>2015</b>                                   | <b>2016</b>                                |
| Annual Performance Objective  | 93          | 93  | 93  | 93  | 93   |

#### Notes - 2011

Source: MD DHMH Vital Statistics Administration, 2010  
2011 data is currently unavailable

This is the number of MD residents recorded births - this DOES NOT include MD residents that gave birth outside the state of MD

#### Notes - 2010

Source: MD DHMH Vital Statistics Administration, 2010

This is the number of MD residents recorded births - this DOES NOT include MD residents that gave birth outside the state of MD

#### Notes - 2009

Source: MD DHMH Vital Statistics Administration, 2009

#### a. Last Year's Accomplishments

The Center for Maternal and Child Health (CMCH) continued to work to improve hospital-specific birth outcomes and to lower neonatal mortality rates by promoting the standard that all very low birth weight (VLBW) infants should be born at Level III perinatal centers. Level I and Level II hospitals should make every effort to keep the number of VLBW births at those hospitals as close to zero as possible. In 2010, more than 89% of very low birth weight infants born in Maryland were delivered at Level III facilities.

In FY 2011, CMCH and MD Vital Statistics Administration (VSA) again provided hospital-specific data on VLBW births and deaths to all birthing hospitals in the State. Data are presented by encoded hospital of birth, and hospitals are grouped into 3 levels of perinatal care, as outlined in the Maryland Perinatal System Standards. The Standards were most recently updated in October 2008 and are available at [http://fha.maryland.gov/mch/perinatal\\_standards.cfm](http://fha.maryland.gov/mch/perinatal_standards.cfm), The Standards were initially developed in 1995 as voluntary standards for Maryland hospitals

providing obstetric and neonatal services. The Standards have been incorporated into the regulations for perinatal referral centers (Level III) by the Maryland Institute of Emergency Medical Services Systems (MIEMSS), and into the Maryland Health Care Commission's State Plan regulations for obstetric units and neonatal intensive care units. The goal of providing hospital-specific data is to improve compliance with the Standards, to reduce the number of VLBW births outside of Level III facilities, and to improve the quality of obstetric and neonatal care in Maryland hospitals.

The Morbidity, Mortality, and Quality Review Committee continued to meet in FY 2011. This State-level multidisciplinary, multiagency committee, established in regulation (36:19 Md R. 1436), is charged with reviewing the incidence and causes of morbidity and mortality related to pregnancy, childbirth, infancy and early childhood. One specific duty of the Committee is to monitor compliance of Level I and Level II hospitals with the Maryland Perinatal System Standards, including the standard that all VLBW infants should be born at Level III perinatal centers. In FY 2011, site visits to all the level I and level II hospitals in the State began.

Title V funding continued to support the Maryland Advanced Perinatal Support Services (MAPSS), a statewide program of telemedicine and on-site high-risk consultation services provided by the State's two academic medical centers to obstetric provider. This service provides outreach education as well as clinical consultations that allow rural patients to remain in their communities rather than traveling to metropolitan areas of the State for specialty consultations.

With the Maryland Patient Safety Center, Title V continued to support a Perinatal Learning Network, a continuation of the Perinatal Collaborative begun in 2006. The Network includes 32 member hospitals, with the goal of improving patient safety in labor and delivery units. Focus areas include improving communication, team building, standardizing electronic fetal monitoring, reducing nosocomial infections, and reducing elective deliveries prior to 39 weeks gestation. CMCH is also participating in a Neonatal Collaborative, initiated in FY 2009 by the Maryland Patient Safety Center. Members include 28 hospitals in Maryland, the District of Columbia and Northern Virginia. The goal of this Collaborative is to improve patient safety in neonatal intensive care units. Focus areas include improving communication, team building, reducing central line-associated bloodstream infections, and standardizing initial resuscitation and stabilization of VLBW infants. With the National Perinatal Information Center, the Collaborative is collecting pre and post-intervention data.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Provide hospital specific data on VLBW births and deaths to Maryland hospitals                   |                          |    |     | X  |
| 2. Collect and analyze perinatal data   |                          |    |     | X  |
| 3. Review, update, and disseminate the MD Perinatal System Standards                                |                          |    |     | X  |
| 4. Provide technical assistance to improve compliance with Standards                                |                          |    |     | X  |
| 5. Support and expand statewide program of telemedicine and on-site high-risk consultation services |                          |    |     | X  |
| 6. Work with the Maryland Patient Safety Center to improve quality of care in hospital settings     |                          |    |     | X  |
| 7.  |                          |    |     |    |
| 8.  |                          |    |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

**b. Current Activities**

This year, the Morbidity, Mortality, and Quality Review (MMQR) Committee continued site visits to all level I and level II hospitals in Maryland to monitor compliance with the Maryland Perinatal System Standards. At each site visit, all VLBW births occurring at the hospital in the prior two year reporting period are reviewed to look for systems issues preventing maternal transport to a level III facility for delivery, and opportunities to improve hospital compliance with the Standards. Administrative oversight for these activities will now fall under the newly created Office of Surveillance and Quality Initiatives (OSQI) within the Maternal and Child Health Bureau.

In 2012, the Perinatal Standards were updated to require all birthing hospitals to develop policies to address non-medically indicated deliveries prior to 39 weeks gestation.

The incorporation of this new standard into the Maryland Perinatal System Standards will allow the Department to continue to monitor such deliveries through hospital site visits by the MMQR, Committee and the Maryland Institute for Emergency Medical Services Systems.

**c. Plan for the Coming Year**

The Office of Surveillance and Quality Initiatives, along with the Vital Statistics Administration, will continue to provide Maryland hospitals with hospital-specific data on VLBW births and deaths, and to monitor perinatal outcomes in the State. These activities will be enhanced by the statewide Morbidity, Mortality, and Quality Review (MMQR) Committee, which will continue to carry out site visits to all level I and level II hospitals in Maryland to monitor hospital compliance with the Maryland Perinatal System Standards, including the standard that all VLBW infants should be born at Level III perinatal centers. OSQI will also begin planning with the Maryland Institute of Emergency Medical Services Systems (MIEMSS) for the next round of site visits of Level III centers.

OSQI will continue work with the Governor's Delivery Unit (GDU) on the Governor's Strategic Goal to reduce infant mortality in Maryland by 10% by 2012. Work will continue on the three specific focus areas of the project: 1.) healthier women before conception, 2.) earlier entry into prenatal care, and 3.) improved perinatal and neonatal care.

**Performance Measure 18:** *Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.*

**Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b>                            | <b>2009</b>                             | <b>2010</b>                             | <b>2011</b>                             |
|--|-------------|--|---|---|---|
| Annual Performance Objective                 | 82.4        | 81                                     | 80                                      | 83                                      | 83                                      |
| Annual Indicator                             | 79.5        | 80.2                                   | 80.2                                    | 56.9                                    | 56.9                                    |
| Numerator                                    | 62068       | 62003                                  | 60129                                   | 41999                                   | 41999                                   |
| Denominator                                  | 78057       | 77268                                  | 74999                                   | 73783                                   | 73783                                   |
| Data Source                                  |             | MD Vital Statistics Annual Report 2008 | MD Vital Statistics, 2009 Annual Report | MD Vital Statistics, 2009 Annual Report | MD Vital Statistics, 2009 Annual Report |
| Check this box if you cannot report the      |             |  |   |   |   |

|   |             |             |             |             |             |
|---|-------------|-------------|-------------|-------------|-------------|
| numerator because<br>1. There are fewer than 5 events over the last year, and<br>2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied. |             |             |             |             |             |
| Is the Data Provisional or Final?   |             |             |             | Final       | Provisional |
|   | <b>2012</b> | <b>2013</b> | <b>2014</b> | <b>2015</b> | <b>2016</b> |
| Annual Performance Objective  | 60          | 60          | 60          | 62          | 62          |

#### Notes - 2011

Source: MD Vital Statistics Administration, 2010 Annual Report  
Data for 2011 are not yet available.

In January of 2010, a new birth certificate was implemented in Maryland. This new birth certificate now records first trimester prenatal care based on date of last menstrual period and the actual date of the first prenatal care visit. In addition, some hospitals experienced difficulties in reporting using the new measure. Therefore, timing of prenatal care initiation data from MD Vital Statistics for 2010 cannot be compared to prior years.

#### Notes - 2010

Source: MD Vital Statistics Administration, 2010 Annual Report

In January of 2010, a new birth certificate was implemented in Maryland. This new birth certificate now records first trimester prenatal care based on date of last menstrual period and the actual date of the first prenatal care visit. In addition, some hospitals experienced difficulties in reporting using the new measure. Therefore, timing of prenatal care initiation data from MD Vital Statistics for 2010 cannot be compared to prior years.

#### Notes - 2009

Source: MD Vital Statistics Administration, 2009 Annual Report

#### a. Last Year's Accomplishments

In 2010, the percentage of Maryland women accessing first trimester prenatal care stood at 56%. When the number of women who did not report prenatal care status are excluded in the denominator this percentage increases to 69%. Both percentages are much lower than the 80.2% reported in 2009. This is a result of a change in the methodology used to collect data on prenatal care usage in the 2010 version of the Maryland birth certificate. As a result, prenatal care data collected in 2010 are not comparable to data collected in earlier years.

Maryland PRAMS Data for 2010 continued to show that the leading reasons why women do not begin prenatal care in the first trimester relate to lack of health care coverage and availability of obstetric services. The top five reasons, in order, were: 1.) couldn't get an appointment, 2.) didn't know she was pregnant, 3.) didn't have a Medicaid card 4.) didn't have insurance or money and 5.) doctor/plan would not start care earlier..

Title V funds continued to support the limited availability of prenatal care clinical services in selected local health departments and home visiting services in other jurisdictions. In Baltimore City, Title V helped to support a team of home visiting nurses and social workers who serve pregnant and postpartum women who are facing the most extreme medical and social hardships.

In several outlying rural areas with limited obstetric capacity, the local health department, either directly or in partnership with a local hospital, supports prenatal clinic services. In Prince George's County, a suburb of Washington, D.C., prenatal care clinics served a largely undocumented population who often lacked access to services elsewhere.

The Maryland Maternal and Child Health Hotline continued to make referrals to prenatal care services in 2011. In State fiscal year 2011, over 700 Marylanders contacted the Hotline to receive Medicaid enrollment forms to support pregnancy and childbirth, while more than 30 women requested a referral for prenatal care services.

The Babies Born Healthy Initiative continued to provide a comprehensive approach to improving perinatal health in 2011. Babies Born Healthy focuses on prevention services and quality improvement. Activities included increasing access to family planning and preconception services; perinatal and neonatal learning networks advancing patient safety for mothers and infants in Maryland hospitals; strengthening provider capacity and expertise with high-risk obstetric consultation via telemedicine and on-site services through a partnership with the State's two academic medical institutions; and establishing standards for obstetric and neonatal care in Maryland's birthing hospitals.

In FY 2011 CMCH continued work with the Governor's Delivery Unit (GDU) to develop a plan to achieve the Governor's Strategic Goal of reducing infant mortality in Maryland by 10% by 2012. The GDU Plan builds on the Babies Born Healthy Initiative by expanding prevention services, improving infrastructure, and building new models and systems of care. Initially, 3 jurisdictions (Baltimore City, Prince George's and Somerset Counties) with high infant mortality rates and racial disparities were targeted. The plan has 3 specific focus areas: 1.) healthier women before conception, 2.) earlier entry into prenatal care, and 3.) improved perinatal and neonatal care. The second focus area directly addresses this performance measure.

In all 3 targeted jurisdictions, local health department sites have implemented "Quick Start" prenatal care programs. Pregnant women identified at service delivery sites are offered expanded screening and referral services, which may include risk assessment, initial exam, screening tests, provision of prenatal vitamins, nutrition counseling, prenatal education, and assistance in accessing ongoing prenatal care. Also, community outreach workers have been deployed in all three jurisdictions to assist women in accessing services.

In FY 2011, Babies Born Healthy Initiative programs and the Governor's Development Unit Initiative continue to focus on prevention services, quality improvement, and data systems development. Dorchester County, a rural jurisdiction on Maryland's Eastern Shore, became a GDU county in 2011 as a result of data showing poor birth outcomes in this rural community.

**Table 4a, National Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Assess and monitor trends in the use of prenatal care  |                          | X  |     |    |
| 2. Refer women to prenatal care services through the MCH Hotline  |                          | X  |     |    |
| 3. Fund local health department-based prenatal care services for low-income uninsured pregnant women                  |                          | X  |     |    |
| 4. Support fetal and infant mortality review processes in every jurisdiction to promote perinatal system improvements | X                        |    |     |    |
| 5. Promote the importance of early prenatal care in home visiting and care coordination programs                      | X                        | X  | X   | X  |



|     |  |  |  |  |
|-----|--|--|--|--|
| 6.  |  |  |  |  |
| 7.  |  |  |  |  |
| 8.  |  |  |  |  |
| 9.  |  |  |  |  |
| 10. |  |  |  |  |

#### **b. Current Activities**

In 2010, CMCH began the application process to receive funding under the new federal Maternal, Infant and Early Childhood Home Visiting Program. Goals for program implementation in at risk communities selected to receive funding to implement evidence based home visiting programs include reducing infant mortality and improving prenatal care usage rates. Funds were initially awarded to two grantees in 2011. The Program expanded services to four additional jurisdictions in Maryland in 2012. Home visitors will promote and tract the use of prenatal care services by enrollees. As a part of benchmarking, data is being collected on the usage of prenatal care services among pregnant women enrolled in the Program.

A revised State Infant Mortality Reduction Plan and a new State Health Improvement Plan were finalized in FY 2012. Both plans call for the promotion of strategies to improve rates of early entry into prenatal care.

A revised State Infant Mortality Reduction Plan and a new State Health Improvement Plan were finalized in FY 2012. Both plans call for the promotion of strategies to improve rates of early entry into prenatal care.

#### **c. Plan for the Coming Year**

Ongoing activities will continue in 2013.

CMCH, with VSA, will continue to the percent of women in Maryland receiving first trimester prenatal care. The Babies Born Healthy and GDU Initiatives will continue to focus on prevention services, quality improvement, and data systems development.

CMCH will work with partners to implement activities and strategies in the State Health Improvement Plan as well the State Infant Mortality Reduction Plan to improve access to quality, comprehensive and timely prenatal care services, particularly for women most at risk. A major focus will be on addressing worsening racial/ethnic disparities in infant mortality and related risk factors. The GDU goal of reducing infant mortality by 10% was met for the overall population in 2009; however, vital statistics data show a worsening of the disparity by race with African American babies now dying at more than three times the rate of White babies. A new goal was set for the GDU Initiative -- to maintain or further improve the overall infant mortality rate and also to reduce the African American rate by 10% by 2012.

### **D. State Performance Measures**

#### **State Performance Measure 1: *Percent of pregnancies that are unintended***

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance                           | 60          | 60          | 60          | 60.5        | 60          |

|                                   |             |                      |                       |                       |                       |
|-----------------------------------|-------------|----------------------|-----------------------|-----------------------|-----------------------|
| Objective                         |             |                      |                       |                       |                       |
| Annual Indicator                  | 56.7        | 42.4                 | 45.5                  | 44.2                  | 44.2                  |
| Numerator                         | 44258       | 28967                | 30359                 | 28739                 | 28739                 |
| Denominator                       | 78057       | 68252                | 66756                 | 65072                 | 65072                 |
| Data Source                       |             | MD PRAMS Report 2007 | MD PRAMS Report, 2009 | MD PRAMS Report, 2010 | MD PRAMS Report, 2010 |
| Is the Data Provisional or Final? |             |                      |                       | Final                 | Provisional           |
|                                   | <b>2012</b> | <b>2013</b>          | <b>2014</b>           | <b>2015</b>           | <b>2016</b>           |
| Annual Performance Objective      | 40          | 40                   | 40                    | 40                    | 40                    |

#### **Notes - 2011**

Source: MD PRAMS Report, 2010; Data for 2011 currently unavailable

#### **Notes - 2010**

Source: MD PRAMS Report, 2010

#### **Notes - 2009**

Source: MD PRAMS Report, 2009

#### **a. Last Year's Accomplishments**

In 2010, the Maryland PRAMS survey estimated that 56% of Maryland pregnancies were intended. Pregnancy intendedness varied by race/ethnicity and was highest for Asian and White Non-Hispanic women, women in their thirties and women with 12 or more years of education. As of 2010, Maryland met the U.S. Healthy People 2020 pregnancy intendness goal of 56%.

The Maryland Family Planning Program works to increase pregnancy intendedness rates in Maryland. With funding from Title X, Title V and state general funds, the Program continued to offer subsidized family planning, preconception health, teen pregnancy prevention and colposcopy services provided to women and men in every jurisdiction in the State. The Title X Maryland Family Planning Program serves approximately 70,000 clients annually at 80 sites. Adolescents represent one fourth of persons served. Title V funds continued to partially support the provision of services in six jurisdictions in 2011.

CMCH continued to work with family planning programs in three jurisdictions: Baltimore City, Prince George's and Somerset counties, as part of a pilot to expand their scope of services to become Comprehensive Women's Health Centers under the Governor's Delivery Unit (GDU) initiative to reduce infant mortality. These programs promote preconception health, screen for chronic disease conditions, and provide mental health and substance abuse prevention counseling for women seen in the clinics. A fourth jurisdiction, Dorchester County, became a pilot site in 2011.

A comprehensive Reproductive Health Life Plan form specific to the Maryland Family Planning Program was developed based on a review of the existing literature and forms from other programs. Clinic staff in the GDU jurisdictions pilot tested and refined the form. In the targeted GDU jurisdictions, the CMCH worked with Medicaid, WIC/Nutrition Services, Mental Health, and other referral sources to insure prompt referral to/from family planning services to maximize women's health before pregnancy. Changes were implemented in Maryland Family Planning Program Data System to track Comprehensive Women's Health services in the targeted jurisdictions and referrals to/from other services.

This past year marked the third year of a three grant awarded to expand family planning clinical service delivery in underserved areas of the State. Strategies include adding new service providers, linking with other community-based providers, and employing clinic efficiency

strategies to enhance the ability to serve additional clients. Reproductive health expansion services are targeted to low income clients, with a focus on teen and Hispanic clients, in the Prince George's County/Greenbelt area. Service delivery partners included a federally qualified health center and the Maryland WIC Program.

The Medicaid Program continued to provide coverage for family planning services to enrollees. In addition, a federal waiver continued to allow the Program to continue coverage for women no longer eligible for Medicaid following pregnancy. Eligible women may receive comprehensive family planning and reproductive health services including contraceptives. However, less than one in three eligible women are receiving services according to Medicaid claims files. Family planning program staff in several jurisdictions, including Baltimore City indicate that many women are still not aware of their eligibility for Medicaid waiver services. This continued to serve as a barrier to care.

Legislation, the Family Planning Works Act, passed in 2011 expanded Medicaid family planning services eligibility to women up to age 51 with family incomes at or below 200% of the federal poverty level. Eligible women must also be U.S. citizens or qualified aliens. Approximately 34,000 Maryland women were expected to be eligible for this expanded fee for service Program that only covers family planning services (e.g., pelvic exams, STI screenings, birth control devices). The Title X and Title V Programs began providing technical assistance to the Medicaid Program to assist with program development and outreach.

**Table 4b, State Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Subsidize family planning and reproductive health clinical services to promote access to care in every jurisdiction in the state   | X                        |    |     |    |
| 2. Conduct a media outreach campaign to increase enrollment in the Medicaid Family Planning Expansion Program   |                          |    | X   |    |
| 3. Distribute family planning brochures to all residents requesting a marriage license and ensure availability of the brochure for distribution at community events and through other departments |                          |    | X   |    |
| 4. Analyze and disseminate PRAMS data on pregnancy intendedness in Maryland   |                          |    |     | X  |
| 5. Continually update and disseminate family planning program administrative and clinical guidelines  |                          |    |     | X  |
| 6. Continue systems changes to promote reconfiguration family planning programs into comprehensive health programs to promote women's wellness before pregnancy                                   |                          |    |     | X  |
| 7. Identify and implement strategies to reduce teen and unintended pregnancies  | X                        | X  | X   | X  |
| 8. Refer Marylanders to family planning services through the MCH Hotline  |                          | X  |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

#### **b. Current Activities**

The Medicaid Family Planning Expansion Program began enrolling eligible women on January 1, 2012. To date, approximately 2,000 women have enrolled.

CMCH was asked to assist with program outreach and promotion activities for the Expansion Program. This year, a brochure was developed for wide dissemination through local health

departments, and other health and social support agencies. In addition, a media campaign, Let's Talk About Birth Control, was developed and launched. The Let's Talk Campaign includes posters, billboards, and transit shelter ads advertising the availability of the Expansion Program and its income eligibility requirements. At risk areas throughout the State are targeted for the Campaign.

#### **c. Plan for the Coming Year**

Ongoing activities will continue in FY 2013. Title V will continue to support the provision of family planning services to reduce unintended pregnancy, a priority of the Maryland Title V Program and to improve perinatal outcomes as family planning is viewed as a key primary prevention strategy.

The expansion of local family planning program sites into comprehensive women's health centers will also continue as additional funding becomes available.

Finally, the impact of the media outreach campaign developed in support of the Medicaid Expansion Program will be assessed.

### **State Performance Measure 2: *Percent of women reporting alcohol use in the last three months of pregnancy***

#### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b>     | <b>2009</b>                  | <b>2010</b>                  | <b>2011</b>                  |
|--|-------------|-----------------|------------------------------|------------------------------|------------------------------|
| Annual Performance Objective                 |             |                 |                              |                              | 10                           |
| Annual Indicator                             |             |                 | 9.9                          | 8.9                          | 8.9                          |
| Numerator                                    |             |                 | 6592                         | 5840                         | 5840                         |
| Denominator                                  |             |                 | 66378                        | 65772                        | 65772                        |
| Data Source                                  |             | MD PRAMS Report | MD PRAMS Report, 2009 births | MD PRAMS Report, 2010 births | MD PRAMS Report, 2010 births |
| Is the Data Provisional or Final?            |             |                 |                              | Final                        | Provisional                  |
|  | <b>2012</b> | <b>2013</b>     | <b>2014</b>                  | <b>2015</b>                  | <b>2016</b>                  |
| Annual Performance Objective                 | 8           | 8               | 8                            | 8                            | 8                            |

#### **Notes - 2011**

Source: MD PRAMS Report, 2010. Data for 2011 is currently unavailable

#### **Notes - 2010**

Source: MD PRAMS Report, 2010

#### **Notes - 2009**

Source: MD PRAMS Report, 2009.

#### **a. Last Year's Accomplishments**

Prenatal alcohol exposure is the leading known cause of mental retardation. Alcohol exposure at any point during fetal development may cause permanent, lifelong disabilities. Fetal Alcohol Spectrum Disorder (FASD), the term given to disorders caused by prenatal alcohol exposure,

was identified as an emerging priority during the 2005 Title V needs assessment. It is estimated that between 700 to 750 new cases of FASD occur in Maryland each year.

In 2010, 9% of Maryland PRAMS mothers reported alcohol use during the last trimester. A smaller percentage (1%) reported binge drinking [defined as 4 or more drinks in one sitting] during the last three months of pregnancy. Alcohol use rates were highest for White women, women 35-39 years of age, and women with a more than a high school education. One in four women reported binge drinking and 54% reported alcohol use before pregnancy. Local health department staff (particularly those in rural areas) surveyed for the Title V needs assessment indicated that they were seeing increasing evidence of alcohol addiction among pregnant women and women of childbearing age.

Maryland has had a statewide FASD Coalition since 2006. The Coalition includes representatives from State agencies (e.g., Education, Juvenile Services, Disabilities), DHMH agencies (e.g., Mental Health, Medicaid), universities and community groups. CMCH provides leadership and staffing for the Coalition and appointed a State FASD Coordinator in 2006. One major Coalition goal is to develop a long range plan for increasing awareness of FASD among all sectors -- health care, substance abuse treatment, social services, education, juvenile services, the faith community, business and industry as well as families and individuals. The Coalition has developed Work Groups to accomplish its tasks. Educational materials (e.g., posters, brochures) and a website have been developed for a public information campaign as mandated by Legislation passed in 2006. The FASD Coalition met quarterly in 2011 with staff support provided by a State FASD Coordinator.

Analysis of Maryland PRAMS data resulted in two FASD publications in 2011:

- 1) Cheng D, Kettinger L, D'Agati D, Lockhart PJ, Hurt L. Alcohol Use Pre-and Late-Pregnancy: Epidemiology and Comments from Postpartum Surveys. In: Pregnancy and Alcohol Consumption. Hauppauge: Nova Science Publishers, 2011
- 2) Cheng D, Kettinger L., Uduhiri K, Hurt L. Alcohol use during pregnancy: prevalence and provider assessment. Obstet Gynecol 2011;116 (2):212-217.

**Table 4b, State Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Provide administrative and staff support for a statewide coalition to address FASD  |                          |    |     | X  |
| 2. Implement a state mandated outreach and education program to raise awareness about FASD. Develop and disseminate outreach materials |                          |    | X   |    |
| 3. Maintain a FASD website   |                          |    |     | X  |
| 4. Hold statewide meetings/conferences to educate providers and other stakeholders about FASD  |                          |    |     | X  |
| 5. Analyze data and publish issue briefs and reports on the problem of FASD in Maryland  |                          |    |     | X  |
| 6.   |                          |    |     |    |
| 7.   |                          |    |     |    |
| 8.   |                          |    |     |    |
| 9.   |                          |    |     |    |
| 10.  |                          |    |     |    |

#### **b. Current Activities**

Activities this year have focused on continuing to promote awareness of FASD to professionals, women, teens and the general public. The FASD Coalition and its sub-committees are developing

a web based FASD toolkit as a resource for women of childbearing age.

CMCH and the FASD Coalition held the State's first FASD conference in September 2007. Planning for a second conference in September 2012 is underway. The conference will feature both local and national experts and was geared towards professionals serving families affected by FASD. Over 150 professionals are expected to attend.

### c. Plan for the Coming Year

In the coming year, the FASD Coordinator along with the FASD Coalition will focus on:

.Finalizing and widely disseminating a comprehensive five year action plan for prevention of FASD and improving the system of care families and individuals affected by FASD.

.Continuing a five year public information campaign based on recommendations in the FASD plan.

.Continuing to conduct continuing education seminars on FASD for physicians, health educators, school health personnel, foster care workers and juvenile justice staff.

.Collaborating with the Department of Juvenile Services on providing a workshop to front line case managers.

.Organizing a curricula on FASD for University of Maryland, School of Social Work.

.Developing three webinars on FASD for educators and consumers.

.Analyzing available data on alcohol use during pregnancy.

.Identifying funding to sustain activities.

### State Performance Measure 3: *Percent of children enrolled in evidence based home visiting programs in Maryland*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b>                          | <b>2009</b>                          | <b>2010</b>                          | <b>2011</b>                          |
|--|-------------|--------------------------------------|--------------------------------------|--------------------------------------|--------------------------------------|
| Annual Performance Objective                 |             |                                      |                                      |                                      | 6                                    |
| Annual Indicator                             |             | 6.0                                  | 6.0                                  | 6.0                                  | 7.4                                  |
| Numerator                                    |             | 2590                                 | 2590                                 | 2590                                 | 4105                                 |
| Denominator                                  |             | 43000                                | 43000                                | 43000                                | 55358                                |
| Data Source                                  |             | Center for Maternal and Child Health | Center for Maternal and Child Health | Center for Maternal and Child Health | Center for Maternal and Child Health |
| Is the Data Provisional or Final?            |             |                                      |                                      | Final                                | Final                                |
|  | <b>2012</b> | <b>2013</b>                          | <b>2014</b>                          | <b>2015</b>                          | <b>2016</b>                          |
| Annual Performance Objective                 | 9           | 9                                    | 9                                    | 9                                    | 9                                    |

#### Notes - 2011

Number of children enrolled in evidence based programs based on reporting from local jurisdictions' home visiting programs, 2011.

Number of children in need based on US Census Bureau ACS, 2011.

**Notes - 2010**

Denominator - Approximate number of low income children in the State

**Notes - 2009**

New Performance Measure, data not available

**a. Last Year's Accomplishments**

Federal funding from HRSA was received to support a coordinated system of early childhood home visiting that has the capacity and commitment to provide infrastructure and supports to assure high-quality, evidence-based practices. These funds will enable Maryland to utilize what is known about effective home visiting services and provide evidence-based programs to promote: improvements in maternal and prenatal health, infant health, and child health and development; increased school readiness; reductions in the incidence of child maltreatment; improved parenting related to child development outcomes; improved family socio-economic status; greater coordination of referrals to community resources and supports; and reductions in crime and domestic violence. In FY 2011, CMCH estimates that 4,105 Maryland children under the age of five were receiving services from one of the seven evidenced based home visiting programs approved for funding under the new home visiting initiative. This represents 6% of the 43,000 poor children under the age of five in the State who are potentially in need of evidence based home visiting services.

In FY 2011, Maryland continued to meet federal requirements for new federal Maternal, Infant and Early Childhood Home Visiting (MIECHV) funds. These requirements included submission of an Updated State Plan and development of benchmarks and a data system. Program staff including a Program director and an epidemiologist were hired.

CMCH submitted the required Updated State Plan in May 2011. The State Plan identifies two of the State's at-risk communities in Baltimore City and the City of Cambridge in Dorchester County for initial funding, and outlined program goals and objectives for the State Home Visiting Program. A State Planning Team was convened to provide guidance on plan development.

Maryland also applied for developmental competitive funding through a federal HRSA/ACF home visiting initiative in 2011, but was unsuccessful. Title V's Early Childhood and Home Visiting Program was also represented on the planning team that is developing Maryland's Race to the Top-Early Learning Challenge Grant application. This State was successful in acquiring these funds.

In September 2011, Maryland was named a "PEW Home Visiting Campaign State." The Pew Home Visiting Campaign promotes and advances smart state and federal policies and investments in high-quality, home-based programs for new and expectant families. The primary focus areas include policy advocacy, research and information sharing. This support affords Maryland the opportunity to bring together policy makers and professionals to promote access to home visiting services.

**Table 4b, State Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Conduct needs assessment and planning activities to identify areas most at risk in the State                          |                          |    |     | X  |
| 2. Fund, monitor and provide technical assistance to evidence based home visiting programs in at risk areas of the State |                          |    |     | X  |
| 3. Collect and analyze data for benchmarking, quality  |                          |    |     | X  |

|   |  |  |  |   |
|---|--|--|--|---|
| improvement and reporting                                   |  |  |  |   |
| 4. Hold quarterly meetings with project subawardees         |  |  |  | X |
| 5. Convene a State Home Visiting Advisory Group             |  |  |  | X |
| 6. Identify funding sources and submit funding applications |  |  |  | X |
| 7.  |  |  |  |   |
| 8.  |  |  |  |   |
| 9.  |  |  |  |   |
| 10.   |  |  |  |   |

#### **b. Current Activities**

The MIECHV Program is providing funding to six of the areas of the State most at risk and in need of expanded home visiting services. The programs are located in Baltimore City, and Prince George's, Washington, Wicomico, Somerset and Dorchester counties. Much of this year's work also centered on acquiring approval of the Program's benchmarks and development of the require data system. Program staff are also working on a proposal in response to the recently released competitive RFA for developmental funding.

In April, Maryland lawmakers unanimously approved legislation, the Home Visiting Accountability Act, designed to strengthen Maryland's network of home visiting programs. The Act requires that at least 75 percent of state funds for home visiting go to evidence based programs. The remainder of the state's investment may support programs that show promise but are still undergoing evaluation. The Act also improves state oversight by requiring that all programs report on the state funds spent, the number and characteristics of families served and child and parent outcomes produced. The reforms are based on the policy framework developed by the Pew Home Visiting Campaign.

#### **c. Plan for the Coming Year**

In 2013, Maryland's MIECHV Program plans to:

- . Monitor and provide technical assistance to local health departments awarded federal funds to expand evidence based home visiting services.
- . Update the 2010 needs assessment once updated Census numbers are released.
- . Implement a quality improvement plan based on data provided by the new data system that became operational in July 2012.
- . Hold quarterly Home Visiting Program Advisory Group meetings and other stakeholder meetings as needed.
- . Continue Title V representation on numerous inter-agency groups addressing home visiting and early childhood issues. These include the Maryland Home Visiting Alliance, the State Early Childhood Advisory Council and any work groups developed to implement the Home Visiting Accountability Act.

#### **State Performance Measure 4: *Rate of emergency department visits for asthma per 10,000 children, ages 0-4***

##### **Tracking Performance Measures**

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b> | <b>2011</b> |
|--|-------------|-------------|-------------|-------------|-------------|
| Annual Performance Objective                 |             |             |             |             | 180         |
| Annual Indicator                             |             | 188.1       | 195.2       | 199.7       | 199.7       |



|   |             |                                     |                                     |                                     |                                     |
|---|-------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
| Numerator                               |             | 7117                                | 7428                                | 7278                                | 7278                                |
| Denominator                             |             | 378334                              | 380606                              | 364488                              | 364488                              |
| Data Source                             |             | HSCRC,<br>Population<br>U.S. Census | HSCRC,<br>Population<br>U.S. Census | HSCRC,<br>Population<br>U.S. Census | HSCRC,<br>Population<br>U.S. Census |
| Is the Data<br>Provisional or<br>Final? |             |                                     |                                     | Final                               | Provisional                         |
|   | <b>2012</b> | <b>2013</b>                         | <b>2014</b>                         | <b>2015</b>                         | <b>2016</b>                         |
| Annual<br>Performance<br>Objective      | 180         | 180                                 | 180                                 | 180                                 | 180                                 |

#### **Notes - 2011**

Source: HSCRC, 2010 ; Population Data from U.S. Census; Data for 2011 currently unavailable

#### **Notes - 2010**

Source: HSCRC, 2010 ; Population Data from U.S. Census;

#### **Notes - 2009**

Source: HSCRC, 2009; Population Data from U.S. Census

#### **a. Last Year's Accomplishments**

The 2012 Maryland Asthma Burden Report indicates that statewide, an estimated 216,000 children have been diagnosed with asthma at some point in their lifetime. This represents 16.4% of children. Averaging 2008-2010 data, an estimated 11.9% of children currently had asthma. Children under the age of 5 had the highest hospitalization rate of any age group at 42.0 hospitalizations per 10,000 population in 2010. Hospitalization rates for African Americans in 2010 were 2.7 times higher than that of Whites (30.0 vs. 11.0 per 10,000). The emergency department visit rate was 5.1 times higher for African Americans as compared to White Marylanders (150.0 vs. 29.7 per 10,000).

The Maryland Asthma Control Program or MACP addresses both pediatric and adult asthma and was administratively housed in CMCH in 2011. The Maryland Legislature mandated establishment of the MACP in 2002 and charged the Program with developing a statewide asthma surveillance system and an asthma control program. Maryland has received a CDC asthma grant since 2001 that supports staff salaries (i.e., an asthma epidemiologist, administrator and evaluator) and funds sub-grantees.

Title V partially supports the costs of administrative staff, program printing and the purchase of educational materials. Project staff provided support for quarterly meetings of both a statewide Asthma Coalition and a MACP Executive Advisory Board. The Program maintains a Website that includes a Maryland Asthma Resource Guide, the most recent asthma surveillance report and other educational materials is available at [www.marylandasthmacontrol.org](http://www.marylandasthmacontrol.org).

Asthma continues to disproportionately affect African American children in Maryland, particularly those living in Baltimore City. Title V funding to the Baltimore City Health Department supported the Childhood Asthma Program. This Program provides outreach, education and home-based case management to families of young children (ages < 6) affected by asthma. Parents/caregivers are educated about the importance of eliminating environmental triggers and proper asthma medical management. The Program serves 150 families annually. In addition, the Latino Health Initiative in Montgomery County Maryland continued to provide outreach and education services to Latino families with Title V support. Services are provided in Spanish.

In 2011, MACP continued to work with the Maryland Department of Education, local departments of education and local health departments to implement the Asthma Friendly Schools Initiative.

Over 60 schools received the designation in school year 2010-2011. Late in 2011, MACP expanded the Initiative to include child care centers and family based programs as designated Asthma Friendly Child Care Centers.

**Table 4b, State Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Administer the Maryland Asthma Control Program (Environmental Health Bureau)   |                          |    |     | X  |
| 2. Continue asthma surveillance activities including annual publication of surveillance reports and briefs                          |                          |    |     | X  |
| 3. Implement the statewide Asthma Control Plan.   |                          |    |     | X  |
| 4. Fund local health department based asthma interventions including support to local and regional asthma coalitions                |                          |    |     | X  |
| 5. Co-chair and provide staff support to the MD Asthma Coalition  |                          |    |     | X  |
| 6. Provide staff support to the Children's Environmental Health Advisory Council  |                          |    |     | X  |
| 7. Collaborate with state and local healthy homes initiatives   |                          |    |     | X  |
| 8. Educate providers about national asthma guidelines to assist in improving patient education and compliance with medical regimens |                          | X  |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

#### **b. Current Activities**

MACP transferred to the Environmental Health Bureau (EHB) on July 1, 2012. Asthma, a leading cause of childhood morbidity, will continue to be a priority focus for the Title V Program. Asthma activities under the EHB that address children and pregnant women will continue to be coordinated with the Title V Program.

Essentials of the Rx for Asthma is a training module for pharmacists to provide community pharmacists with evidence-based interventions to assist patients with asthma to better understand their condition and manage their treatment. This program offers pharmacists strategies to improve asthma outcomes in patients as well as tools to implement best practices in a community practice environment. In 2012, MACP began working with the University of Maryland, School of Pharmacy to train pharmacists in retail settings on the Essentials module. The training will target 75 pharmacists working in geographic areas with high asthma prevalence.

Medicaid data on pharmacy claims, provider visits and hospitalization rates continued to be used to target outreach and education efforts in 2012.

#### **c. Plan for the Coming Year**

Proposed asthma activities for 2013 will include:

- . Implementing and expanding the Asthma Friendly School and Child Care Initiatives.
- . Developing an asthma action plan to reduce asthma disparities. With funding from the ECCS grant, the Baltimore City Health Department is currently conducting interviews with families whose children are affected by asthma. The results will be compiled, analyzed and summarized for a report to be released next year on ways to improve asthma outreach and education for African American families.
- . Promoting healthy environments to lessen the impact of asthma. MACP will continue its

partnership with a national coalition to educate child care providers concerning the effects of the indoor environment on asthmatic children. This Healthy Homes approach includes in-home education and home assessment for asthma triggers within Prince George's County and in Dorchester County.

- . Educating parents/caregivers, patients and the public about asthma prevalence, treatment and best practices management. The University of Maryland Breathmobile will continue to receive support to conduct education and case management for asthmatic children in Baltimore City. Activities and outreach will take place to educate providers and health officials concerning the updated NAEPP Guidelines.

- . Maintaining and expanding the asthma surveillance system.

- . Continuing to support and maintain the Maryland Asthma Coalition and Executive Committee. The Executive Committee serves as an advisory group to MACP staff and guides the Coalition in creation and implementation of asthma specific outreach programs.

**State Performance Measure 5:** *Percent of children ages 5-17 enrolled in the Maryland Medicaid Program whose BMI  $\geq$  85% of normal weight for height*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b>                             | <b>2010</b>                             | <b>2011</b>                             |
|--|-------------|-------------|---|---|---|
| Annual Performance Objective                 |             |             |   |   | 39                                      |
| Annual Indicator                             |             |             | 40.6                                    | 40.2                                    | 40.2                                    |
| Numerator                                    |             |             | 118823                                  | 125722                                  | 125722                                  |
| Denominator                                  |             |             | 292955                                  | 313130                                  | 313130                                  |
| Data Source                                  |             |             | Healthy Kids Study 2009; MA enroll data | Healthy Kids Study 2010; MA enroll data | Healthy Kids Study 2010; MA enroll data |
| Is the Data Provisional or Final?            |             |             |   | Final                                   | Provisional                             |
|  | <b>2012</b> | <b>2013</b> | <b>2014</b>                             | <b>2015</b>                             | <b>2016</b>                             |
| Annual Performance Objective                 | 39          | 38          | 38                                      | 38                                      | 38                                      |

**Notes - 2011**

MD Medicaid, Healthy Kids Study, 2010

Enrollment data from Maryland Medicaid, December 2010

Data for 2011 are not yet available.

**Notes - 2010**

MD Medicaid, Healthy Kids Study, 2010

Enrollment data from Maryland Medicaid, December 2010

**Notes - 2009**

MD Medicaid, Healthy Kids Study, 2009 dataset

Enrollment data from Maryland Medicaid: December 2009

**a. Last Year's Accomplishments**

Surveillance data on overweight and obesity among Maryland children and adolescents is limited, but improving. Data sources continue to include the Maryland Youth Risk Behavior Survey (2011 is the latest year), the Maryland Youth Tobacco survey, BMI data collected by the WIC Program

through the Maryland Pediatric Nutrition Surveillance System, and Medicaid data collected from chart reviews. The most recent data from the National Survey of Children's Health for the year 2007 provides statewide estimates of the percentage of children, ages 10-17, who are overweight or obese. An estimated 13.3% were obese and another 16.6% were at risk for being overweight. African American (42%) and Hispanic (32%) children were more likely than White (24%) children to be classified as overweight/obese. The 2011 YRBS report similarly estimates that one in four Maryland youth were overweight or obese in 2011 (defined as greater than the 85th percentile for body mass index).

The reduction of childhood overweight/obesity has been identified as a priority issue in recent Title V MCH needs assessments and in the Maryland State Health Improvement Plan (SHIP) completed in 2011. The SHIP's goal is to reduce the percentage of obese children in the State from a baseline of 11.9% in 2010 to 11.3% in 2014.

The Office of Chronic Disease Prevention (OCDP) had lead responsibility for addressing overweight/obesity in Maryland in 2011. A full time childhood wellness coordinator manages programmatic activities. CMCH continued to collaborate with OCDP to address childhood obesity through strategic planning, surveillance, provider education, research translation, and public awareness initiatives. The State Advisory Council on Heart Disease and Stroke with state support from OCDP continued to maintain a Childhood Obesity subcommittee. This subcommittee brings together statewide stakeholders to provide strategic direction and oversight to childhood obesity initiatives.

In 2011, Dr. Cheryl DePinto continued to lead childhood obesity prevention activities for CMCH and served on the American Academy of Pediatrics, Maryland Chapter, Childhood Obesity Committee, which partners with CMCH and the OCDP on obesity prevention strategies, outreach, and education. Additionally, she served as the liaison to OCDP in implementing the Maryland Nutrition and Physical Activity Plan.

Last year, DHMH launched ChopChop Maryland magazine to engage families in planning, cooking, and dining together to protect against childhood obesity. ChopChop Maryland uses social media strategies including Facebook and text messaging to provide families monthly newsletters highlighting easy, healthy recipes based upon seasonal Maryland ingredients. DHMH also encouraged fresh fruit and vegetable consumption through the Fruits and Veggies More Matters mass transit marketing campaign in the Summer of 2011 to correspond with the farmers market season.

Throughout 2011, DHMH worked closely with the University of Maryland Baltimore and its President, Dr. Jay Perman, to further two major health initiatives that encompass childhood obesity. The first is the President's Clinic, which engages students from UMB Schools of Medicine, Nursing, Dentistry, Social Work, Pharmacy, and Law to work as a team to provide better and more cost-effective patient care by drawing on the expertise of each team member. Secondly, the University is combating childhood obesity by promoting practices and community programs that encourage healthy behaviors and lifestyles among youth and their families.

In November 2011, DHMH worked with the University of Maryland Baltimore to co-sponsor a two day Summit on Childhood Obesity to address the growing issue of childhood obesity in Maryland. Over 400 stakeholders from across the state attended and several national experts participated in the Summit including Dr. William Dietz of the CDC and Dr. John Ruffin of NIH. Follow-up activities include the establishment of the Institute for a Healthiest Maryland, which engages higher education experts from Maryland's colleges and universities to provide evidence-based resources coordinate training and technical assistance, and support communication and best practice dissemination efforts by maintaining an interactive website and email network.

**Table 4b, State Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Collaborate with the Cancer and Chronic Disease Bureau, WIC and others to plan and implement strategies to reduce childhood overweight and obesity           |                          |    | X   | X  |
| 2. Work with the MD AAP, Medicaid and others to improve surveillance  |                          |    |     | X  |
| 3. Work with the Cancer and Chronic Disease Bureau to implement the Community Transformation Grant  |                          |    |     | X  |
| 4. Support implementation of referral networks and other services for children who are overweight or obese  |                          |    |     |    |
| 5. Promote awareness of childhood obesity among health providers, families, schools, and the general public through presentations and funding of pilot programs |                          |    | X   | X  |
| 6.  |                          |    |     |    |
| 7.  |                          |    |     |    |
| 8.  |                          |    |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

**b. Current Activities**

Several activities have focused on improving early childhood wellness. The School Health Interdisciplinary Program (SHIP) is an annual continuing education opportunity that provides intensive training on all components of coordinated school health. In July 2012, an early childhood obesity prevention training will be provided through a SHIP session on Let's Move child care. This year, Title V ECCS funds were used to support a pilot demonstration project to improve healthy eating and physical activity habits among young African American children enrolled in child care and their parents in a rural Maryland community. Title V is now exploring further expansion of the program.

A recent Johns Hopkins University study found that more than a third of Baltimore neighborhoods are located in food deserts where residents don't have ready access to healthy foods. In February 2012, DHMH became a member of the Maryland Fresh Food Retail Task Force to help to identify opportunities for retailing of healthy foods. The Food Trust facilitates this task force, which brings together multiple sectors and organizations throughout the state to address food deserts where children do not have access to healthy foods.

**c. Plan for the Coming Year**

During 2013, Maryland will continue to promote healthier environments for preschool and school age children through collaboration with the Maryland State Department of Education regarding child care and school wellness initiatives by participating in the Health and Physical Education Advisory Committee and the Maryland State School Health Council. Strengthening childcare licensing standards to align with Caring for our Children (CFOC): National Health & Safety Performance Standards for Early Care and Education Programs (3rd Ed.) specific to nutrition, physical activity and screen time standards is a goal for 2013.

Additionally, a Health and Wellness Designation for early care and education programs with enhanced nutrition, physical activity, and screen time practices will be developed by DHMH and MSDE as part of Tiered Quality Rating and Improvement System (Maryland EXCELS) implementation.

The Title V Program and the OCDP will continue to partner with the Maryland Chapter of the

American Academy of Pediatrics to improve child care wellness, support local school wellness policy implementation and monitoring, and identify best practices for children who are overweight/obese. Many MD-AAP members provide leadership for childhood obesity prevention by supporting both community and state-level strategies that improve physical activity and nutrition opportunities.

**State Performance Measure 6:** *The percent of youth with special health care needs (YSHCN) families who participate in transition planning for their child.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| Annual Objective and Performance Data | 2007 | 2008 | 2009 | 2010                        | 2011                                   |
|---------------------------------------|------|------|------|-----------------------------|--|
| Annual Performance Objective          |      |      |      |                             | 40                                     |
| Annual Indicator                      |      |      |      | 36.8                        | 48.9                                   |
| Numerator                             |      |      |      | 161                         | 111                                    |
| Denominator                           |      |      |      | 438                         | 227                                    |
| Data Source                           |      |      |      | 2010 Maryland Parent Survey | 2012 Transitioning Youth Parent Survey |
| Is the Data Provisional or Final?     |      |      |      | Final                       | Provisional                            |
|                                       | 2012 | 2013 | 2014 | 2015                        | 2016                                   |
| Annual Performance Objective          | 50   | 53   | 55   | 57                          | 57                                     |

**Notes - 2011**

This is the first year of reporting for this performance measure, and data comes from the FY12 administration of the Maryland Transition Youth Parent Survey. The Annual Indicator, 48.9%, corresponds to the number of respondents to the survey who reported participating in any type of transition planning for their YSHCN. almost 49% of families report having participated in some type of transition planning for their child. Among those families who reported participating in some type of transition planning (111), 72% (80 families) participated in transition planning through their child's IEP only; 2.7% participated in health care transition planning only; and 25% (28 families) participated in transition planning through their child's IEP and also participated in health care transition planning. These data are provisional.

**Notes - 2010**

This is baseline data for this performance measure, and it comes from the 2010 Maryland Parent Survey for the 2010 Title V Needs Assessment. Subsequent years' data will come from annual surveys of Maryland parents about transition issues, to be conducted through the Parents' Place of Maryland with assistance from Maryland Title V program for CYSHCN.

The rate is calculated by taking the number of respondents who report having a child with special health care needs aged 13 to 21 years (the denominator, n=438), and who answered 'yes' to having participated in the development of a transition plan for their child (the numerator, n=161.) It is important to note that 163 of the 438 respondents did not answer this question; 99 respondents answered "no"; and 15 answered "don't know." If this measure was calculated using only those respondents who answered this particular question (161/275), the rate would be 58.5%.

**a. Last Year's Accomplishments**

Youth transition to adulthood is one of the six core outcomes identified by the federal Maternal and Child Health Bureau for children and youth with special health care needs (CYSHCN). Maryland's Office for Genetics and Children with Special Health Care Needs (OGCSHCN) is the Title V CSHCN program for the state and will be directing many of the activities around youth healthcare transition for YSHCN over the next five years. Please see the 'Last Year's Accomplishments' section under National Performance Measure 6 for additional discussion of Title V activities around transition in FY11. Both quantitative and qualitative data collected for Maryland's 2010 Title V Needs Assessment indicate that Maryland is struggling to ensure that all YSHCN receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. According to the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), Maryland ranked 40th in the nation on achieving this core outcome; less than 37% of Maryland families of YSHCN aged 12 to 17 reported that their child received the services necessary to make appropriate transitions to adult life. During FY10, Youth Transition to Adulthood was identified as a state-level priority for Title V programs in Maryland, and stakeholders agreed that because participation in transition planning is an important step for families and YSHCN, and increasing the proportion of parents of YSHCN who report engaging in transition planning from pediatric to adult health care has been identified as a Healthy People 2020 objective, that transition planning should be the focus for the performance measure for this priority.

The baseline data for this performance measure comes from the 2010 Maryland Parent Survey, which indicated that among all respondents with a YSHCN aged 13 years or older only 36.8% reported participation in transition planning for their child. The data for the FY11 reporting year comes from the 2012 Transitioning Youth Parent Survey, a survey developed by OGCSHCN, the Parents' Place of Maryland (PPMD), the Maryland State Department of Education (MSDE), and the Maryland Center for Developmental Disabilities (MCDD) with input from the Maryland Department of Disabilities (MDoD) and piloted during FY11. According to this survey, almost 49% of families report having participated in some type of transition planning for their child. Among those families who reported participating in some type of transition planning (111), 72% (80 families) participated in transition planning through their child's IEP only; 2.7% participated in health care transition planning only; and 25% (28 families) participated in transition planning through their child's IEP and also participated in health care transition planning.

There are several state agencies in Maryland which focus on providing resources to support youth transition and transition planning around post-secondary education, employment, housing and independence, including MSDE and DORS (Division of Rehabilitation Services), the Developmental Disabilities Administration (DDA), MDoD, MCDD, and an Interagency Transition Council (IATC). In FY11, OGCSHCN decided to partner with these agencies and others whenever possible and to focus as an agency primarily on health care transition (HCT) issues in the state, because no other agency was making HCT a focus and because so few parents report having participated in HCT planning for their YSHCN. OGCSHCN created a Transition Coordinator staff position in FY11, created a HCT section of its website, and planned to hold a series of HCT conferences, primarily for families, in FY12 in partnership with PPMD. OGCSHCN worked with MSDE towards inclusion of HCT information in their Transition Planning Handbook for families -- local transition coordinators for the school system were provided supplemental HCT materials, developed by OGCSHCN, to distribute to families along with the Handbook during IEP meetings for students aged 14 years and older.

**Table 4b, State Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Develop, pilot, and conduct the Transitioning Youth Parent Survey in partnership with The Parents' Place of Maryland (PPMD). |                          |    |     | X  |

|   |   |   |  |   |
|---|---|---|--|---|
| 2. Support PPMD in providing individual assistance and training to families and providers around transition issues including transition planning information.           |   | X |  | X |
| 3. Plan to subcontract with PPMD for 3 day-long regional Health Care Transition conferences for families, youth and providers.  |   | X |  | X |
| 4. Support monthly Transition Lecture Series for youth, families and providers hosted by Kennedy Krieger/Maryland Center for Developmental Disabilities.                |   | X |  | X |
| 5. Support transition clinic activities including clinics for youth with sickle cell disease and youth with diabetes.   | X | X |  |   |
| 6. Support the Interagency Transition Council in their annual statewide conference for families and professionals and conduct a presentation on health care transition. |   |   |  | X |
| 7. Develop health care transition planning materials for inclusion in the Maryland State Department of Education's Transition Planning Guide.                           |   |   |  | X |
| 8.  |   |   |  |   |
| 9.  |   |   |  |   |
| 10.   |   |   |  |   |

#### **b. Current Activities**

The OGCSHCN Transition Coordinator hired in FY11 left the position and the position was quickly filled with an experienced project manager and health educator who is establishing strategic partnerships with various agencies and organizations (including The Arc, DDA, MCDD, MSDE and DORS, and the IATC) to develop a statewide strategic plan for health care transition. OGCSHCN supported the IATC statewide conference and staff presented about health care transition (HCT) there. OGCSHCN is identifying resources for youth transition to include in their Resource Database so that families and providers can locate existing services. OGCSHCN continued to fund transition clinics and the transition lecture series. OGCSHCN and PPMD conducted the Parent Survey for Transitioning Youth. A Youth Transition Fact Sheet based on 2009-10 NS-CSHCN data was developed and disseminated by OGCSHCN. OGCSHCN and PPMD conducted 3 HCT Conferences for a total of 94 participants including families, youth and providers in Central and Western Maryland and on the Eastern Shore. Participants received HCT resources and two training tracks were offered -- one for families and one for youth. Families were trained on topics including HCT planning and social security benefits, and youth received training on managing their own health care and the changes their bodies go through in puberty and young adulthood.

#### **c. Plan for the Coming Year**

Goals for the HCT strategic plan include improving clinical HCT services for YSHCN; developing a list of medical providers who treat adults with SHCN; identifying/adapting resources to support youth/families/providers to plan for HCT; providing technical assistance to OGCSHCN grantees who work with YSHCN; ensuring that YSHCN are members of youth advisory councils and groups in Maryland; and improving state and local capacity to collect, share, analyze and disseminate HCT data and information to evaluate transition program goals. The Transition Coordinator will disseminate the plan to partners in other agencies/organizations for feedback and suggestions; portions of the plan will be implemented during FY13. Additional findings to consider for incorporation into the statewide plan come from the Maryland Community of Care Consortium (CoC) and activities for OGCSHCN and PPMD's planning grant from HRSA/MCHB to improve health and related services for CYSHCN with autism (ASD) and other developmental disabilities (DD). At a quarterly CoC meeting at the end of FY11, CoC members suggested several strategies to improve transition outcomes for Maryland YSHCN, including a focus on HCT, training the adult health care system to work with YSHCN and families, and providing focused legal guidance on estate planning and guidance on guardianship. The planning grant is



charged with development of a statewide plan to improve services for CYSHCN with ASD and other DD; PPMD and OGCSHCN are taking a regional approach to plan development and several regions within the state have identified HCT as a top regional priority for this population. The plan that is developed will be coordinated with OGCSHCN's statewide HCT plan to maximize efforts and resources.

Data gathered from the FY12 Parent Survey for Transitioning Youth will be analyzed, shared and disseminated and the survey will be conducted again during FY13. Findings from the FY12 analysis will be used to guide program planning and activities and for reporting for the state level priority performance measure. The state performance measure is related to parents' participation in transition planning for their YSHCN.

Partnering with and enhancing current activities around building advocacy and self-management skills for YSHCN in Maryland is already underway, with plans to expand efforts in FY13. OGCSHCN will provide training and resources on HCT to youth through various local and statewide youth groups and councils and will promote YSHCN representation on youth advisory councils, including the Governor's Youth Advisory Council.

OGCSHCN Transition Coordinator is building on the success of the FY12 HCT Conferences and planning three more regional health care transition conferences to take place during FY13. Plans to add an additional training track for providers are being considered. OGCSHCN will continue to enhance its statewide resource database to include a comprehensive list of transition resources for families.

**State Performance Measure 7:** *The percent of Maryland Community of Care Consortium for CSHCN (CoC) members who report 5 or more collaborative activities with Consortium partners in the previous 12 months.*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| <b>Annual Objective and Performance Data</b> | <b>2007</b> | <b>2008</b> | <b>2009</b> | <b>2010</b>  | <b>2011</b>  |
|--|-------------|-------------|-------------|--|--|
| Annual Performance Objective                 |             |             |             |  | 53   |
| Annual Indicator                             |             |             |             | 51.8   | 42.9   |
| Numerator                                    |             |             |             | 29   | 15   |
| Denominator                                  |             |             |             | 56   | 35   |
| Data Source                                  |             |             |             | 2008 Maryland Community of Care Partnership Profil | 2011 Maryland Community of Care Partnership Profil |
| Is the Data Provisional or Final?            |             |             |             | Final  | Provisional  |
|  | <b>2012</b> | <b>2013</b> | <b>2014</b> | <b>2015</b>  | <b>2016</b>  |
| Annual Performance Objective                 | 42.9        | 49          | 53          | 57   | 61   |

#### Notes - 2011

This baseline measurement comes from the 2011 "Maryland Community of Care Partnership Profile," a survey conducted every two years by the Maryland Community of Care Consortium. Several important caveats to consider when interpreting this measure and comparing it to the 2008 baseline data listed for 2010 are: (1) 2008 participants were asked about collaborations in the past 2 years; FY11 participants were asked about collaborations during the past year only; (2) comparisons are of 2 cross sections of COC participants; a subset will have responded at both

time points, but these data do not reflect that; and (3) a decrease in the measure from 2008 to FY11 is not necessarily negative if, in fact, the decrease is driven by a different mix of participants. Further analysis of the FY11 data will reveal what drove the change. FY11 provides a good baseline to measure improvements from FY11 to FY15.

#### **Notes - 2010**

This baseline measurement comes from the 2008 "Maryland Community of Care Partnership Profile," a survey conducted yearly every two years by the Maryland Community of Care Consortium. Respondents (members of the Consortium) report on the number and types of collaborations they have had in the past year with other Consortium member organizations.

#### **a. Last Year's Accomplishments**

Supporting the development/implementation of systems of care for CYSHCN has been identified as a critical objective for states by the federal MCHB; state Title V programs have been asked to work with family advocates, providers, and other partners to achieve success on the 6 core outcomes for CYSHCN. Ongoing stakeholder partnerships were identified in the 2010 Title V Needs Assessment as the primary method through which several core outcomes for CYSHCN in Maryland should be addressed. Stakeholders agreed that the improvement of these outcomes requires a system-oriented, partnership-based approach that incorporates infrastructure, population-based services, enabling services, and direct services and that strong, ongoing partnerships/collaborations in the design and implementation of services for CYSHCN and their families, as well as leadership at the state level have become critical in Maryland.

In 2008, a key partner of the state's Title V program for CSHCN (the Office for Genetics and Children with Special Health Care Needs, or OGCSHCN) - the Parents' Place of Maryland (PPMD) - was awarded a federal "State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs" in partnership with OGCSHCN. Through the grant and partnerships, PPMD/OGCSHCN developed the Maryland Community of Care Consortium for CSHCN (or CoC.) Since its inception, the CoC Consortium has created a broad alliance of diverse stakeholders in collaborative efforts to improve systems of care for Maryland CSHCN and their families. The CoC has been a leader in building and sustaining partnerships among members while successfully advancing the goals of Title V programs in Maryland. Stakeholders at the aforementioned MCH meeting also concurred that the role of the CoC is essential to the health of Maryland's Title V program. Much of the CoC's work is aligned with the Healthy People 2020 objective to increase the proportion of CSHCN who receive their care in family-centered, comprehensive, coordinated systems (MICH HP2020-14.) For more specifics on how the CoC addresses the 6 core outcomes, please see the discussions for NPMs 2-6 and SPM 6 in this report. Also, please see the Public Input, Agency Capacity, and State Agency Coordination sections of this report for more on how OGCSHCN leverages strategic partnerships in order to improve outcomes for CYSHCN.

During FY11, there were 4 quarterly meetings of the CoC with a total of over 160 attendees; 34% of attendees were from local, state, or federal government agencies; 25.4% were parents of CYSHCN; 27.9% were from parent or non-profit organizations; 7.6% were from universities or hospitals, 11.9% were from insurance providers; and 7.6% were from professional organizations.

The CoC conducted a survey at the 2008 Summit to determine the extent of collaboration among CSHCN stakeholders in Maryland, which was designed to document how and to what degree the consortium activities are influencing meaningful working relations among the partners -- parents, providers, advocates, administrators, consumers, and professionals from public, private, and nonprofit sectors at both the state and community levels. Summit participants were asked to complete a chart indicating whether or not their organization interacted with listed agencies/programs specifically on behalf of CYSHCN in the past 2 years (baseline) and if so, which activities they engaged in. At that time, 57% of summit attendees reported between 5 or more collaborative activities. It was agreed that this composite measure of partnerships among CYSHCN stakeholders should be the performance measure for this priority area. The measure

was taken again in 2011 among ongoing CoC members, with 42.9% reporting 5 or more collaborative activities in the previous year. Several important caveats to consider when interpreting this measure are (1) 2008 participants were asked about collaborations in the past 2 years; FY11 participants were asked about only the past year; (2) comparisons are of 2 cross sections of COC participants; a subset will have responded at both time points, but these data do not reflect that; and (3) a decrease in the measure from 2008 to FY11 is not necessarily negative if, in fact, the decrease is driven by a different mix of participants. Further analysis of the FY11 data will reveal what drove the change. FY11 provides a good baseline to measure improvements from FY11 to FY15.

**Table 4b, State Performance Measures Summary Sheet**

| Activities  | Pyramid Level of Service |    |     |    |
|---|--------------------------|----|-----|----|
|   | DHC                      | ES | PBS | IB |
| 1. Act as a key partner and member of the leadership team for the Maryland Community of Care (CoC) Consortium for CYSHCN.   |                          |    |     | X  |
| 2. Educate CoC members about Title V CYSHCN Maryland programs and responsibilities, engage them in ongoing needs assessment activities, and solicit CoC input for program priorities and implementation strategies.                           |                          |    |     | X  |
| 3. In partnership with PPMD, plan and hold 4 quarterly meetings of the CoC to address current issues and priorities for Maryland CYSHCN and to provide a forum for joint-problem solving, partnership building, collaboration and networking. |                          |    |     | X  |
| 4. Build and strengthen partnerships with local health departments serving CYSHCN through providing funding, convening yearly regional meetings, and involvement in ongoing state-level Title V CYSHCN activities.                            |                          |    |     | X  |
| 5. Build and strengthen partnerships with other programs within DHMH including CMCH, VSA, the Mental Hygiene Administration.  |                          |    |     | X  |
| 6. Use OGCSHCN's Systems Development Grants program to build and strengthen partnerships with academic and community partners through mechanisms including recommended partnerships, joint initiatives, and an annual grantee meeting.        |                          |    |     | X  |
| 7.  |                          |    |     |    |
| 8.  |                          |    |     |    |
| 9.  |                          |    |     |    |
| 10.   |                          |    |     |    |

#### **b. Current Activities**

The CoC has been funded since 2008 by a HRSA D70 State Implementation grant. PPMD, the fiscal agent for the grant, was awarded a no-cost extension with remaining funds to continue to CoC through FY12; funding will then continue through state Title V CYSHCN funds. PPMD is the main partner of OGCSHCN in building the infrastructure for a comprehensive, community based, culturally competent, family centered, user-friendly system of care for CYSHCN. Each year, the CoC gives out several mini-grants with the purpose of supporting community-based efforts to build infrastructure for CYSHCN and their families; FY12 awards included support for the Abilities Network for improving systems for children with epilepsy, a regional consortium in the mid-eastern shore region of the state, and a support consortium for Hispanic families and providers. The CoC meetings incorporate trainings for CoC members on Title V CSHCN and the Needs Assessment process, and CoC meeting attendees are regular contributors to the Title V CYSHCN process. FY12 meetings focused on addressing regional disparities among CYSHCN,

input into ongoing Title V CYSHCN activities, and how best to address adequate insurance and financing issues in the state. A smaller subset of CoC members will be formed to address this.

### c. Plan for the Coming Year

In FY13, quarterly meetings of the CoC will be held and the mini-grants program will continue. Support for the mid-Eastern Shore and Latino Family Support consortia will continue - these consortia are identifying existing services and gaps and building new partnerships in order to creatively fill gaps and bring needed services to under-served families. OGCSHCN hopes to move to a regional center model for the service system for CYSHCN and their families, in which each region of the state has a regional center with a hub. The hub would consist, minimally, of a care coordination/case management position, a parent navigator position, and will have a phone number and website that can be used by families of CSHCN and YSHCN in finding assistance and services related to their special health needs and will be a connection center for local health departments, primary care pediatricians and specialty providers, providers of related services, mental health and oral health providers, child care providers, etc. within each region that provide or are interested in providing services to CYSHCN and families. OGCSHCN received an innovative proposal for FY14 for increasing the availability of pediatric subspecialty care for CYSHCN on the Eastern Shore through a partnership between a local hospital, local health department and management board, and primary and specialty care providers; this proposed partnership formed partially as a result of the mid-Shore consortium bringing these partners together for regular interactions and discussions of need and strategy. In FY13 there are plans to start a consortium for Western Maryland, another rural area in which there are very few community-based services for CYSHCN.

In FY13 and in future years, the CoC will be funded through OGCSHCN's Systems grant to PPMD. In addition to the partnerships formed and strengthened through the CoC, OGCSHCN works to build and strengthen partnerships outside of the CoC and has working relationships with the following agencies/offices within DHMH: the Center for Maternal and Child Health, the Laboratories Administration, Environmental Health Protection and Tracking Program, Vital Statistics Administration (VSA), the Developmental Disabilities Administration, and Medicaid. Other state agencies that OGCSHCN works with include the Department of Disabilities, the Interagency Transition Council, the Maryland State Department of Education (MSDE), 22 of the 24 Local Health Departments in Maryland, and the Maryland Center of Excellence for Developmental Disabilities. In addition to these government entities, OGCSHCN works with numerous community organizations on a regular basis and is forging new partnerships with Maryland's Mental Hygiene Administration around telehealth in rural regions of the state and with Maryland State Department of Education around the early childhood Race to the Top grant around developmental screening.

**State Performance Measure 8:** *Percent of performance measure benchmarks Maryland has reached in implementing a Data Sharing plan among it's Title V programs and other government and non-government agencies and organizations.*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

| Annual Objective and Performance Data | 2007 | 2008 | 2009 | 2010             | 2011             |
|---------------------------------------|------|------|------|------------------|------------------|
| Annual Performance Objective          |      |      |      |                  | 16               |
| Annual Indicator                      |      |      |      | 0.0              | 33.3             |
| Numerator                             |      |      |      | 0                | 2                |
| Denominator                           |      |      |      | 6                | 6                |
| Data Source                           |      |      |      | Maryland Title V | Maryland Title V |

|                                   |             |             |             |              |              |
|-----------------------------------|-------------|-------------|-------------|--------------|--------------|
|                                   |             |             |             | Program Data | Program Data |
| Is the Data Provisional or Final? |             |             |             | Final        | Final        |
|                                   | <b>2012</b> | <b>2013</b> | <b>2014</b> | <b>2015</b>  | <b>2016</b>  |
| Annual Performance Objective      | 33          | 50          | 67          | 100          | 100          |

#### **Notes - 2011**

This measure is based on how many (numerator) of 6 (denominator) benchmarks have been reached: Performance measure benchmarks toward implementing an effective data sharing plan for increased data integration are as follows: 1. Assess data sharing needs 2. Identify barriers to data sharing and propose recommendations to overcome them 3. Develop an implementation plan 4. Obtain feedback from stakeholders on implementation plan and make necessary adjustments 5. Pilot test the implementation plan 6. Implement the plan.

The numerator for FY11, 2, reflects that the first two benchmarks have been completed.

#### **Notes - 2010**

This measure is based on how many (numerator) of 6 (denominator) benchmarks have been reached: Performance measure benchmarks toward implementing an effective data sharing plan for increased data integration are as follows: 1. Assess data sharing needs 2. Identify barriers to data sharing and propose recommendations to overcome them 3. Develop an implementation plan 4. Obtain feedback from stakeholders on implementation plan and make necessary adjustments 5. Pilot test the implementation plan 6. Implement the plan.

As 2010 was the year the measure was developed, no progress was made during that year, so the measure for 2010 is zero.

#### **a. Last Year's Accomplishments**

Consistent data that indicates the well-being of Maryland's CYSHCN population is crucial to measuring the state's progress on the six core outcomes for this population. Data availability is limited due to agency silo issues and fragmentation among government and non-government agencies and organizations serving CYSHCN in Maryland. The data most commonly used to measure Maryland's performance around the six core outcomes come from two national surveys, the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN.) While these provide valuable data every four years and allow state-to-state and state-to-nation comparisons of critical data points and outcomes, they do not provide yearly or jurisdiction-level data that would help Maryland target limited resource to improve outcomes for CYSHCN. At a needs assessment stakeholder meeting in March, key Title V CSHCN staff and parent advocates, working together as a group, identified the lack of data sharing among agencies as one of the most significant barriers in planning and implementing strategies to improve core outcomes for CYSHCN in Maryland.

Maryland collects state- and jurisdiction-level data that would be useful to analyze and evaluate on behalf of CYSHCN and other maternal and child health populations, however in many instances this information is either not made available to or easily accessed by the state's Title V CSHCN program, the Office for Genetics and Children with Special Health Care Needs (OGCSHCN). Even when data are easily accessible, it is not always integrated in such a way as to make analysis/evaluation feasible in a timely manner. Examples include: Infant Hearing Screening (or EHDI ) program data; Birth Defects (BDRIS); long-term follow-up for metabolic disorders and sickle-cell disease; Maryland Assessment Tool for Community Health (MATCH); Maryland Pregnancy Risk Assessment Monitoring System (PRAMS); and Children's Medical Services (CMS) for CYSHCN.

Greater data sharing, systems development, and integration would enable state agencies to improve state and local capacity to collect/analyze/share/translate/disseminate MCH data and

evaluate programs, resulting in a more comprehensive assessment of Maryland's achievement and progress for each of the six CYSHCN core outcomes. This may lead to more efficient use of state and partner resources, resulting in better health outcomes for Maryland CYSHCN. To this end, a primary focus of Title V in Maryland for the next five years will be to enhance data sharing among Maryland's Title V CSHCN program, the Center for Maternal and Child Health, and other state and local government and non-government agencies and organizations in order to better target state efforts to improve systems of care for CYSHCN and to provide timely information to stakeholders. The benchmarks for this measure are as follows: 1. Assess data sharing needs; 2. Identify barriers to data sharing and propose recommendations to overcome them; 3. Develop an implementation plan; 4. Obtain feedback from stakeholders on implementation plan and make necessary adjustments; 5. Pilot test the implementation plan; 6. Implement the plan. In FY11 2 of the 6 benchmarks were completed.

In FY11, through the SSDI grant, a consultant was hired to convene and lead a Data Work Group among the programs in Maryland's Family Health Administration (FHA) within the Department of Health and Mental Hygiene. This work group identified data needs among all participating programs in FHA and is focused on 3 main areas- Access, Support, and Standards. Through this data work group, OGCSHCN completed much of the needed work around benchmarks one and two of this performance measure with its partners, including CMCH. OGCSHCN also assessed data sharing needs and began identifying barriers to sharing with external partners- projects include data collaboration activities with the Vital Statistics Administration and Maryland State Department of Education. The infant hearing screening program initiated and integrated a statewide online data management system for the Maryland Early Hearing Detection and Intervention Program. which allows for virtually real time data sharing which facilitates more timely and accurate follow up and improved continuity of hearing health care. OGCSHCN also worked with Maryland's Community of Care Consortium (CoC) for CSHCN in developing an action plan for this state priority.

**Table 4b, State Performance Measures Summary Sheet**

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Engage in intensive strategic planning to build internal data linkages within OGCSHCN.  |                          |    |     | X  |
| 2. Engage in strategic planning with other partners (such as CMCH, VSA, and MSDE) to strengthen data linkages among various agencies serving CYSHCN.               |                          |    |     | X  |
| 3. Hire a database manager to build OGCSHCN capacity to collect, manage and analyze data.  |                          |    |     | X  |
| 4. Plan to overhaul existing OGCSHCN program databases, including BDRIS and Sickle Cell Disease.   |                          |    |     | X  |
| 5. Participate in the FHA data workgroup to identify data needs among all participating programs in FHA and focus on 3 main areas- Access, Support, and Standards. |                          |    |     | X  |
| 6.   |                          |    |     |    |
| 7.   |                          |    |     |    |
| 8.   |                          |    |     |    |
| 9.   |                          |    |     |    |
| 10.  |                          |    |     |    |

**b. Current Activities**

In FY12, the work of the Data Workgroup continued. OGCSHCN developed an implementation plan for this priority (in support of benchmark # 3) and reorganized its overall strategic plan; enhancing internal and external data linkages and reporting systems was identified as a focus for

this priority. Goals include development of a grantee database; improvement of a resource database; and completion of consolidation of BDRIS, IHP and CCHD screening databases with linkages to Maryland's Infant and Toddlers program and VSA. OGCSHCN hired a database manager in FY12; this has greatly expanded program capacity to organize and analyze data. OGCSHCN's Sickle Cell Disease Program database was rebuilt. OGCSHCN/PPMD conducted the Parent Survey for Transitioning Youth. Various fact sheets using state and regional data to show unmet needs by Maryland region and state level performance on core outcomes for CYSHCN were developed/disseminated. OGCSHCN staffed the Data Workgroup of the Maryland Commission on Autism which identified forging data linkages among state agencies, academic institutions and community organizations as a major priority. OGCSHCN partnered with the Maryland Center for Developmental Disabilities to plan development of a grantee database that would allow OGCSHCN to measure progress on the 6 core outcomes according to Title V funded activities throughout the state.

### **c. Plan for the Coming Year**

At the start of FY13, the branch of the Maryland Department of Health and Mental Hygiene (DHMH) that houses OGCSHCN was reorganized, and as a result a new Maternal and Child Health Bureau was created. Both OGCSHCN and CMCH are part of this new Bureau, as well as WIC. It is possible that this will enhance data linkage opportunities among these programs. Also, DHMH has created a Virtual Data Unit (VDU) which is designed to facilitate data access for internal and external users through mechanisms such as a common access portal and help desk, as well as to coordinate and prepare responses to data requests that involve multiple data units of DHMH. Both of these developments should facilitate more linkages among various data sets within DHMH. CMCH has plans to share data collected in a survey about medical homes among Maryland pediatricians with OGCSHCN. During FY13, OGCSHCN will continue to implement its internal plan to improve data systems and sharing, will pilot the external strategic plan to improve data systems and sharing, and will continue to solicit feedback from partners (assessing data needs and barriers to sharing will be continual throughout this Needs Assessment cycle.)

Maryland applied for and was awarded funding from the Centers for Disease Control and Prevention (CDC) for funding to finance these enhancements to OGCSHCN's Infant Hearing Program (IHP) eSP™ database. These enhancements will improve the state's ability to capture complete and accurate demographic data on all infants born in a hospital and create direct electronic links with hospitals and doctors and with the ITP. Maintaining the eSP™ database is crucial to the operability of OGCSHCN's follow-up programs for CSHCN and the database provides a powerful platform to create linkages between OGCSHCN, CMCH, and other databases.

OGCSHCN, in partnership with The Parents' Place of Maryland, has plans through SSDI funding to enhance the multi-year Transitioning Youth Parent Survey by having it translated into Spanish and hiring parents to conduct the survey face-to-face in underserved areas and populations within Maryland. OGCSHCN/PPMD also has plans to conduct the Maryland Parent Survey, first administered in 2010, to inform ongoing needs assessment activities of the CYSHCN population in Maryland. Results of these surveys will be analyzed, shared with partners, and disseminated widely in the state.

OGCSHCN also intends to continue building its resource database for families and providers and will focus on the creation of a web portal to access this database.

## **E. Health Status Indicators**

Child death rates have continued to decline in Maryland. Maryland has a Child Fatality Review Process operational in every jurisdiction in the State.i

Strategies to maintain and/or improve the death rate due to intentional injuries among children aged 14 and younger include the assessment of deaths by the Child Fatality Review Teams (CFRT) that exist in every jurisdiction in Maryland. The teams review and analyze each death and report any community/systems issues that impacted or contributed to the death. Recommendations are made to the community to prevent any recurrences. These recommendations may include the need for policy changes, community education and resource development.

The former Center for Maternal and Child Health and now the Office of Surveillance and Quality Initiatives provides administrative support to the CFRT. The CFRT receives reports on child deaths from the Office of the State Medical Examiner and these reports form the foundation of the case reviews.

In 2011, the State CFR focused on amending the law to allow local CFR teams to participate in a system of electronic data entry offered free to states by the National Center for Child Death Review. Over time, participation in this system will improve state data and allow for better understanding of child deaths and improve planning to address them. Additionally, there has been on-going focus on injury prevention in relation to MVC's. Also, Safe Sleep remains an area of great concern and teams are encouraged to use and promote the trainings offered by the Center for Infant and Child Loss which focuses its efforts on safe sleep. Likewise, CMCH staff participate in meetings and trainings offered by the Partnership for a Safer Maryland and Safe Kids, two organizations dedicated to injury prevention.

## **F. Other Program Activities**

MCH Hotline/Children's Resource Line: The MCH/Medicaid Programs operate an 800 number telephone line for MCH outreach, information and referral (1-800-456-8900). This line is located and operated by the Medical Assistance Program and is used to provide information and education about the Medical Assistance Program as well as to refer callers to MCH providers.

***/2013/ Office for Genetics and Children with Special Health Care Needs (OGCSHCN) operates the Children's Resource Line (1800-638-8864); staffed by a parent of a CSHCN who assists parents and caregivers find resources for CSHCN; can accommodate both English and non-English-speaking families. //2013//***

Web Sites: Both the Center for Maternal and Child Health ([www.fha.state.md.us/mch](http://www.fha.state.md.us/mch)) and the Office for Genetics and Children with Special Health Care Needs ([www.fha.state.md.us/genetics](http://www.fha.state.md.us/genetics)) provide functional Websites. These web sites include information about all programs funded or provided, as well as information about the Title V program, including linkage to a copy of the complete Title V report for the most recent fiscal year.

Child Abuse and Neglect: The Legislature charged DHMH to establish a Child Abuse and Neglect Center of Excellence Initiative within DHMH. Responsibility for administering this Initiative was placed within CMCH. The Center of Excellence trains providers in each region of the State to diagnose and treat child abuse and neglect. Legislation passed in 2006 establishes the Children's Trust Fund under DHMH to fund the Child Abuse and Neglect Centers of Excellence using funds derived from the sale of commemorative birth certificates. CMCH recently revised and updated the Commemorative Birth Certificate brochure promotes the Children's Trust Fund.

Emergency Preparedness: Emergency preparedness is an important priority concern for DHMH. DHMH recently consolidated the Office of Public Health Response and the Office of Emergency Response into a single unit reporting directly to the Deputy Secretary for Public Health. This was done to ensure that activities are coordinated. CMCH has also begun to prepare for a range of



emergency situations that would benefit from a coordinated MCH approach. A CMCH protocol has been developed and staff are continuing to meet to discuss the role of MCH within the DHMH emergency preparedness program. Title V will continue to take an active role in promoting H1N1 vaccinations.

**Conferences and Training:** The MCH Program recognizes the importance of enhancing public health competency through ongoing training and education. It achieves this activity by providing training opportunities to LHD public health personnel in important MCH domains such as home visiting, school and adolescent health, screenings and surveillance and asthma education. Several conferences are annually supported by the MCH Program. These include the annual reproductive health update, the annual school health institute, an asthma summit, a perinatal health conference, and technical assistance workshops for local health departments.

/2012/ Stakeholder meetings are planned as the new Affordable Care Act programs (e.g., home visiting, PREP) are implemented. //2012// **/2013/ OGCSHCN conducts and supports multiple conference and training activities, including parent trainings in collaboration with PPMD, stakeholder conferences and training, grantee technical assistance meetings, regional LHD trainings, and healthcare transition conferences. //2013//**

**Women's Health:** An Office of Women's Health was established within CMCH in 2001 with the goal of promoting wellness for Maryland women throughout the lifespan. Activities of this Office include the publication and dissemination of reports (e.g., chartbook on the health status of Maryland women; postpartum depression); promotion of inter and intra-agency coordination on women's health issues, and implementation of a statewide model for integrating preventive health screening into family planning programs.

/2012/ CMCH hosted the annual Women's Health Steering Committee meeting in May 2011. Findings from the 2009 PRAMS report were highlighted. A revised Women's Health Chartbook will be published in 2011. //2012// **/2013/ The 2012 meeting was held in May. //2013//**

**Sudden Infant Death Syndrome:** Title V monies will continue to support the Maryland SIDS Project at the Center for Infant and Child Loss, University of Maryland School of Medicine. This Center provides SIDS outreach and education as well as counseling to support families experiencing the death of a child.

**Environmental Health Tracking System:** The Community Health Administration continued to work with the Environmental Public Health Tracking Program's network implementation grant from the CDC. The Family Health Administration, including CMCH and OGCSHCN, will be involved in grant development. The grant references the need for collaboration with a variety of data sources important to Title V including the birth defects registry, hospital discharge data, vital statistics and the childhood lead registry. CMCH provides staff support for the Children's Environmental Health Advisory Council and worked to complete a Children's Environmental Health Indicator Report.

The OGCSHCN is working with the Environmental Public Health Tracking Program' to post data on birth defects for public uses on the web as per the CDC protocol. The Maryland Tracking Network went live and displays birth defects data. The Environmental Public Health Tracking Program and OGCSHCN also worked together in FY11 to create and print a Providers' Manual for the BDRIS program to be distributed to hospitals and facilities. The manual educates providers on reporting information requirements and guidelines to assist them in ensuring that their institutions are compliant with the State of Maryland Birth Defects Reporting mandate. In addition, the manual provides an overview of Maryland's BDRIS and can serve as a training tool for new employees responsible for the reporting requirements for institutions. A Care Notebook for families has also been created and will be provided in paper or electronically to all newly identified families in OGCSHCN follow up programs.

**Autism Spectrum Disorders (ASD):** During the 2005 session, legislation was passed requiring the Maryland Dept of Education, in collaboration with the DHMH, to establish a pilot program to study

and improve screening practices for Autism Spectrum Disorders. Title V has participated in several meetings focused on Autism Spectrum Disorders. In FY11 OGCSHCN partnered with The Parents' Place of Maryland (PPMD) in applying for a HRSA State Planning Grant to improve systems of care for children with ASD and other developmental disorders. If awarded, this funding would allow for (1) development of a project leadership team to guide planning activities; (2) completion of a comprehensive regional and statewide needs assessment of the target population; (3) incorporation of input from diverse stakeholders and establishment of advisory councils from each region of the state in developing the needs assessment and state plan; and (4) evaluation and documentation of strengths and needs of current developmental screening and medical home initiatives. ***//2013/ This funding was awarded and activities are underway. //2013//***

OGCSHCN is also funding Baltimore City and The Harriet Lane Clinic in a quality improvement initiative for developmental screening in pediatric practices. This project improves the rates with which pediatric primary care providers in Baltimore City effectively screen young children for developmental delays. An article describing the findings was published in a peer-reviewed journal in FY10. The project has expanded into practices outside of Baltimore City and over 25 practices have now been trained. ***//2013/ This project is expanding to other regions of the state. //2013//***

## **G. Technical Assistance**

Maryland's Office for Genetics and Children with Special Health Care Needs is requesting Technical Assistance around National Performance Measure # 5- percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. We have distinct regional disparities in Maryland where families in certain regions of the state (Eastern Shore, Western Maryland, and Southern Maryland) do not have adequate access to needed primary and specialty medical care, mental health services, oral health services, and related services such as speech, occupational, and physical therapies, as well as other types of services. We are considering a regional center model similar to states like Pennsylvania and Virginia.

OGCSHCN hopes to move to a regional center model for the service system for CYSHCN and their families, in which each region of the state has a regional center with a hub. The hub will consist, minimally, of a care coordination/case management position, a parent navigator position, and will have a phone number and website that can be used by families of CSHCN and YSHCN in finding assistance and services related to their special health needs. Ideally, the regional hubs will also house a resource/training room for parents and providers with computers, scanners, printers, and a library available for families' use. The hubs will be a connection center for local health departments, primary care pediatricians and specialty providers, providers of related services, mental health and oral health providers, child care providers, etc. within each region that provide or are interested in providing services to CYSHCN and families.

OGCSHCN would like assistance in organizing conference calls or meetings with other state CSHCN programs who have regional centers, as it would be beneficial to learn from their experiences and expertise. Virginia and Pennsylvania have regional models, any if there are any other states that HRSA/MCHB Title V know of, OGCSHCN would like to consult with those states as well.

Other technical assistance needs may be discussed at the August review meeting with the Maternal and Child Health Bureau.

## V. Budget Narrative

Budget and expenditure data from Forms 3, 4, and 5 are provided for the application year, interim year, and reporting year to assist the reviewer in analysis of the budget and expenditure narrative. For complete financial data, refer to all the financial data reported on Forms 2-5, especially when reviewing the federal allocation on Form 2 for the 30%/30%/10% breakdown for the budgets planned for primary and preventive care for children, children with special health care needs, and administrative costs.

### Form 3, State MCH Funding Profile

|   | FY 2011   |           | FY 2012   |          | FY 2013   |          |
|---|-----------|-----------|-----------|----------|-----------|----------|
|   | Budgeted  | Expended  | Budgeted  | Expended | Budgeted  | Expended |
| <b>1. Federal Allocation</b><br>(Line1, Form 2)   | 11953971  | 11940135  | 11863538  |          | 11872051  |          |
| <b>2. Unobligated Balance</b><br>(Line2, Form 2)  | 0         | 0         | 0         |          | 0         |          |
| <b>3. State Funds</b><br>(Line3, Form 2)          | 8965479   | 8624571   | 8897654   |          | 9176099   |          |
| <b>4. Local MCH Funds</b><br>(Line4, Form 2)      | 0         | 0         | 0         |          | 0         |          |
| <b>5. Other Funds</b><br>(Line5, Form 2)          | 0         | 0         | 0         |          | 0         |          |
| <b>6. Program Income</b><br>(Line6, Form 2)       | 0         | 0         | 0         |          | 0         |          |
| <b>7. Subtotal</b>                                | 20919450  | 20564706  | 20761192  |          | 21048150  |          |
| <b>8. Other Federal Funds</b><br>(Line10, Form 2) | 129454241 | 129454241 | 131150864 |          | 242519544 |          |
| <b>9. Total</b><br>(Line11, Form 2)               | 150373691 | 150018947 | 151912056 |          | 263567694 |          |

### Form 4, Budget Details By Types of Individuals Served (I) and Sources of Other Federal Funds

|   | FY 2011  |          | FY 2012  |          | FY 2013  |          |
|---|----------|----------|----------|----------|----------|----------|
|   | Budgeted | Expended | Budgeted | Expended | Budgeted | Expended |
| <b>I. Federal-State MCH Block Grant Partnership</b> |          |          |          |          |          |          |
| <b>a. Pregnant Women</b>                            | 2586320  | 2387383  | 2698788  |          | 2507937  |          |
| <b>b. Infants &lt; 1 year old</b>                   | 2802689  | 2183533  | 2293249  |          | 2465619  |          |

|   |           |          |           |  |           |  |
|---|-----------|----------|-----------|--|-----------|--|
| <b>c. Children 1 to 22 years old</b>  | 8577383   | 9059958  | 8920381   |  | 9006415   |  |
| <b>d. Children with Special Healthcare Needs</b>  | 5589845   | 5514493  | 5638784   |  | 5632560   |  |
| <b>e. Others</b>  | 1003213   | 1022127  | 771297    |  | 1031118   |  |
| <b>f. Administration</b>  | 360000    | 397212   | 438693    |  | 404501    |  |
| <b>g. SUBTOTAL</b>  | 20919450  | 20564706 | 20761192  |  | 21048150  |  |
| <b>II. Other Federal Funds (under the control of the person responsible for administration of the Title V program).</b> |           |          |           |  |           |  |
| <b>a. SPRANS</b>  | 437274    |          | 2380865   |  | 140000    |  |
| <b>b. SSDI</b>  | 93713     |          | 93737     |  | 100000    |  |
| <b>c. CISS</b>  | 0         |          | 0         |  | 0         |  |
| <b>d. Abstinence Education</b>  | 0         |          | 486550    |  | 530058    |  |
| <b>e. Healthy Start</b>   | 0         |          | 0         |  | 0         |  |
| <b>f. EMSC</b>  | 0         |          | 0         |  | 0         |  |
| <b>g. WIC</b>   | 112043869 |          | 109561818 |  | 112449752 |  |
| <b>h. AIDS</b>  | 0         |          | 0         |  | 0         |  |
| <b>i. CDC</b>   | 8546040   |          | 9986860   |  | 120388778 |  |
| <b>j. Education</b>   | 0         |          | 0         |  | 0         |  |
| <b>k. Home Visiting</b>   | 0         |          | 0         |  | 1301284   |  |
| <b>k. Other</b>   |           |          |           |  |           |  |
| <b>Family Planning</b>  | 4307837   |          | 4573336   |  | 4302533   |  |
| <b>Hearing Detection &amp; Injury</b>   | 0         |          | 0         |  | 146657    |  |
| <b>Newborn Screening</b>  | 1387061   |          | 0         |  | 1317723   |  |
| <b>PREP</b>   | 0         |          | 0         |  | 237271    |  |
| <b>Primary Care/Rural H</b>   | 0         |          | 0         |  | 949458    |  |
| <b>Injury Prevention</b>  | 0         |          | 757924    |  | 656030    |  |
| <b>PHHS</b>   | 0         |          | 1342988   |  | 0         |  |
| <b>Preventive Health S</b>  | 0         |          | 1966786   |  | 0         |  |
| <b>Primary Care/Rura</b>  | 2032809   |          | 0         |  | 0         |  |
|   | 605638    |          | 0         |  | 0         |  |

**Form 5, State Title V Program Budget and Expenditures by Types of Services (II)**

|                                       | <b>FY 2011</b>  |                 | <b>FY 2012</b>  |                 | <b>FY 2013</b>  |                 |
|---------------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                       | <b>Budgeted</b> | <b>Expended</b> | <b>Budgeted</b> | <b>Expended</b> | <b>Budgeted</b> | <b>Expended</b> |
| <b>I. Direct Health Care Services</b> | 2529026         | 2073565         | 3766140         |                 | 3668159         |                 |
| <b>II. Enabling Services</b>          | 7839371         | 7381515         | 6174671         |                 | 5773945         |                 |
| <b>III. Population-</b>               | 2850823         | 4705258         | 5236577         |                 | 4890938         |                 |

|   |          |          |          |  |          |  |
|---|----------|----------|----------|--|----------|--|
| <b>Based Services</b>   |          |          |          |  |          |  |
| <b>IV. Infrastructure Building Services</b>                   | 7700230  | 6404368  | 5583804  |  | 6715108  |  |
| <b>V. Federal-State Title V Block Grant Partnership Total</b> | 20919450 | 20564706 | 20761192 |  | 21048150 |  |

## A. Expenditures

This section describes Title V expenditures for FFY 2011 and notes any trends and shifts in expenditures as compared to previous years. During FFY 2011, the Maryland joint federal-state Title V Program expended \$20,564,706 for services and activities to promote the health of women, infants, and children including those with special health care needs. With the federal funds, the State met the 30-30-10 budgeting requirement, with 40% of federal funds allocated for children with special health care needs and 46% allocated for preventive and primary care services for children. Less than 10% of federal funds were used for administration.

By level of the MCH pyramid, the majority of Title V -- State partnership funds supported activities at the infrastructure (31%) and enabling levels (36%). Direct services represented 10% of expenditures and included direct medical care for children with special health care needs in tertiary medical and medical day care centers. Direct care services were also provided by family planning clinical providers in several jurisdictions as well as prenatal care and well child care clinical services that continued to be offered by a limited number of local health departments. Population based services represented 23% of total expenditures in 2011. These services included newborn screening for metabolic disorders, screening for blood lead exposure, immunizations, and vision and hearing screening in the schools.

The first notable shift in funding allocation occurs in FY 1999 with the advent of MCHP making children in families with incomes up to 200% FPL eligible for Medicaid services. Direct expenditures went from 61% to 28% in one year. This continued to decrease as Maryland's Medical Assistance Program assumed a greater fiscal role, including covering more unique CSHCN services.

During this same time period, the percentage of expenditures for enabling services also increased. This was due to more local health departments providing care coordination services in lieu of direct services. Most of the current funding for these services has been in prenatal and early infant home visiting of the families most at risk for poor maternal and birth outcomes. This shift also occurred as the State Title V Agency educated and notified local health departments that combined, the majority of Title V dollars, should be allocated for enabling, population-based services and infrastructure development.

/FY2012/OGCSHCN

During the past year, OGCSHCN underwent an administrative and structural realignment to better meet the needs of Maryland's CYSHCN population as identified through the 2010 Needs Assessment. The OGCSHCN was re-engineered to increase effectiveness and efficiency, and strategies were developed to create a focus on collaboration and teamwork both internally and with external partners.

As part of this structural realignment, OGCSHCN worked with internal and external stakeholders, including families and grantees, to review the MCH Funding and Services pyramid and evaluate how it categorizes its programs, services, grants, and other activities by pyramid level. This resulted in a large shift in categorizations between what constitutes infrastructure building and

direct services. Several large OGCSHCN grants had been classified as infrastructure building prior to the OGCSHCN reorganization. After the evaluation, the services provided through these grants were reclassified, mostly as direct services, to be in alignment with the MCHB pyramid definitions.

This redefinition also helped to drive the direction of strategic planning, including budgets, for FY 2013 (the first year significant programmatic and budgeting changes ~~/2013/ will //2013//~~ be implemented.) ~~//2012//~~

## **B. Budget**

Maryland's Maternal and Child Health Block Grant supports vital programs and services for women and children in Maryland, including those with special health care needs. The Title V MCH Program is jointly administered by the Center for Maternal and Child Health (CMCH) and the Office for Genetics and Children with Special Health Care Needs (OGCSHCN) under the auspices of the Family Health Administration. The Department of Health and Mental Hygiene has a strong commitment to core public health functions and essential public health services to Maryland's families and children.

The Maternal and Child Health Program budgets and functions reflect an evolving public health responsibility that complements and enhances the current health delivery system, recognizes recent legislative changes in health and mandated public health functions, the uniqueness of the populations being served, and emerging research and standards of care affecting the health status of MCH populations. Maryland's Title V budget for FY 2013 is projected to total \$21,048,150 including \$11,872,051 in federal funds and \$9,176,099 in State funds and reflects a decrease in federal block grant funding since 2006. The State share in MCH services meets the requirements for the State match. Maryland meets the maintenance of effort requirement of Sec. 505 (a)(4).

Maryland continues to allocate Maternal and Child Health Block Grant funds using criteria that include: (1) MCH priority needs based on statewide and community assessments, (2) local health department fiscal shortfalls within the identified core categories, (3) poverty rates and estimated size of the maternal and child population (birth-21 years of age), (4) performance measures and outcome measures and (5) the availability of other funding sources. An example of this is the MCHP expansion which enabled funds to be reallocated from direct services for CSHCN to other population groups ineligible for MCHP. Funds may be reallocated throughout the year when unexpected needs are identified. (Budgets are developed two years prior to authorized spending. For example during the summer of 2011, the MCH Budgets for FY 2012 were developed. During the 2012 Legislative Session, the FY 2013 budget was approved).

Throughout the two-year budget process, but particularly during the budget development and the revision phase (based on legislative authorized budget), the MCH Offices evaluate the MCH Service Pyramid fiscal allocation to ensure that it reflects the spirit and intent of MCHB. Throughout the year, quarterly meetings are held between the MCH Offices and the Budget Personnel to determine current expenditure levels and expected expenditure for the remainder of the year. It is during these meetings that budget shortfalls and funds to be reallocated are identified. Throughout the year, all contracts including LHD grants are tracked through the procurement process and subsequently monitored for appropriate and timely expenditures, and adherence to DHMH fiscal procedures.

During the development and subsequent expenditure of the MCH budget, the grant is fiscally and programmatically monitored to ensure that the funding levels adhere to the "30-30-10" Title V requirement. For FFY 2013, it is proposed that federal funding for each Title V population will be distributed accordingly: preventive and primary care for children -- 46.2%, CSHCN --39.9% and

Administration -- 3.4%. The other category at 10.5% refers to the maternal and infant health population. By level of the MCH pyramid, it proposed that total federal-state funding will be distributed as follows: direct services - \$3,668,159 or 17.4%; enabling services - \$5,773,945 or 27.4%; population based -- \$4,890,938 or 23.2% and infrastructure building services - \$6,715,108 or 31.9%.

In FFY 2013, a total of \$9,006,415 in State and federal funds are budgeted to support preventive and primary care programs and services for children and adolescents. These funds will support activities that promote and protect the health of Maryland's 1.7 million children and adolescents, ages 0-21, by assuring that comprehensive, quality preventive and primary services are accessible. Activities and strategies will include:

- . Early Childhood Initiatives, including home visiting, early childhood mental health and promotion of access to a medical home;
- . Childhood Lead Screening Program, which promotes increased blood lead testing, particularly in "at risk" areas;
- . Childhood Asthma Program activities including partnership building and implementation of interventions, planning, and surveillance;
- . School health programs, including medical consultation and development of guidelines related to issues such as childhood nutrition and obesity; and provision of population based services (immunizations, vision and hearing screening, lead screening); and
- . Child Fatality Review, the goal of which is to prevent child deaths by developing an understanding of the causes and incidence of child deaths.

In FY 2013, a total of \$4,973,556 in state and federal funds is budgeted for programs and services to prevent maternal and infant deaths and improve the health care system for women of childbearing age and the 75,000+ babies born each year in Maryland. Activities and strategies will include:

- . Statewide voluntary Perinatal Standards, and perinatal systems building activities in each jurisdiction, including maternal, fetal and infant mortality reviews, and perinatal center review and designation;
- . Sudden Infant Death Syndrome (SIDS) educational and family support activities;
- . Statewide initiatives (Babies Born Healthy and the Governor's Delivery Unit) to reduce infant mortality and eliminate racial disparities in birth outcomes;
- . A statewide survey to improve pregnancy outcomes (PRAMS);
- . Promotion of infant breastfeeding;
- . Care coordination services and home visiting for pregnant women and infants;
- . Fetal alcohol spectrum disorder (FASD) prevention activities; and
- . Family planning/reproductive health clinical services.

***//2013/ In FY 2013, a total of \$4,738,295 (federal) //2013//*** is budgeted for programs and services to address children with special health care needs. Activities and strategies will include:

. **Payment for Medical/Clinical Services**

Through the Children's Medical Services Program, payment for direct specialty care and related services is made to providers for uninsured and underinsured children who meet the medical and financial eligibility criteria for the program.

. **Genetic Services**

Funding is also provided for a statewide system of clinical genetic services, including infrastructure support for 3 Genetics Centers, ***//2013/ 9 //2013//*** Outreach Clinics, the Comprehensive Hemophilia Treatment Center, pediatric and transition (adolescent/young adult) Sickle Cell Disease Clinics and specialized biochemical genetics laboratory services.

. **Birth Defects Program**

The Birth Defects Reporting and Information System (BDRIS) collects data on birth defects to estimate birth defects prevalence, track trends and conduct surveillance for changes in trends that could be related to environmental hazards. BDRIS also uses the full resources of the OGCSHCN to provide families with information and referrals.

. Medical Day Care for CSHCN

Two medical day care programs designed specifically for medically fragile infants and young children are funded by the Program. These unique centers provide skilled nursing services in a child care setting for children ages 6 weeks to 5 years who have complex medical conditions and whose needs cannot be met in traditional child care programs.

. Local Health Department Grants

In addition to funding local health departments for core public health activities, funds are also provided specifically for CSHCN services and programs. Outreach specialty clinics are still funded in some jurisdictions, but most jurisdictions have replaced actual clinics with gap-filling care coordination, outreach, information/referral, dissemination of resource information, and needs assessment activities. The local health departments also administer the respite care funds provided through the local health department grants.

. Respite Programs and Special Camps

Enabling services are growing in Maryland. In addition to the PKU and Sickle Cell Disease camps that have been funded for many years, specialty camps for children **/2013/ who are blind, deaf, and hard of hearing are now being supported //2013//**. Local health departments are now funding a variety of respite services as well as increasing community capacity for providing them with grant funds provided by the OGCSHCN.

. Parent Involvement Activities

Parental involvement in policy and program development is supported through a grant to Parent's Place of Maryland (PPMD), a non-profit, family-directed and staffed center serving parents of children with disabilities and special health care needs. PPMD also houses the Maryland chapter of Family Voices. PPMD and OGCSHCN have an ongoing partnership in a number of activities. These include the Family-to-Family Health Education and Information Center, which provides families of CYSHCN with a central source of information and education about the health care system as well as direct family support and referrals as well as the Maryland Community of Care Consortium for CSHCN. The Consortium is funded by a grant from the federal Maternal and Child Health Bureau and offers a forum for information exchange, problem solving, consensus building, and collaborative action to address gaps and barriers in services for children with special health care needs (CSHCN) and their families. **/2013/ Through a contract with Parent's Place of Maryland, a newly established program, "Parent Connections" is designed for parent mentors who also have a child or children who are deaf or hard of hearing, to provide emotional support for parents when they learn their child has a hearing loss. Parent mentors are trained to provide personal support and resources. //2013//**

. CSHCN Systems-Building Activities

System-building activities include grants to four Centers of Excellence (Johns Hopkins, University of Maryland, Children's National Medical Center, and Kennedy Krieger Institute) to support a Resource Liaison at each center whose function is to assist families of CYSHCN to find needed resources both within the centers and within the community. In some centers, these individuals may work directly with particular clinics and play a greater role in coordinating the care of CYSHCN. **/2013/ During FY12, the Improving Medical Home Partnerships for Specialty Access through Coordination and Training (IMPACT) program was completed and will be introduced to specialty care providers in FY13. Through an MOU between OGCSHCN and the University of Maryland, this project developed specialty modules to prepare medical home providers to better handle common specialty concerns in their offices. A collaborative care agreement has also been developed for use by practices that participate in the specialty module training. Additionally, an evaluation component was added to**



**determine system impact on health outcomes. //2013//**

**. Youth Transition to Adulthood**

**/2013/ Through a contract with Parent's Place of Maryland, three regional health care transition conferences were held across the State for families and youth with special health care needs transitioning from a pediatric to an adult medical home in FY12. These conferences took place the Eastern Shore, Central Maryland and Western Maryland. These conferences will be held at other locations throughout the state of Maryland over the next four years. The conferences addressed various aspects of health care transition, and included themes on legal concerns (such as consent issues, advanced directives); financial concerns (such as insurance coverage, estate planning); medical concerns (finding a provider, having a summary document for new provider, fostering as much independent chronic illness management as possible); and, psychological/social concerns (impact of chronic illness on self-esteem/independence/sexuality; social impact of chronic illness; impact of health on work; self-advocacy). Each conference was a full day in length and included lunch. There was a plenary session and breakout sessions in the morning and in the afternoon. A couple of breakout session were specifically designed for, and attended by youth. Each conference had a session that involved a panel of young adults with special health care needs. //2013//**

**. Data Development**

Projects include data collaboration activities with the Vital Statistics Administration and Maryland State Department of Education. The infant hearing screening program has initiated and integrated a statewide online data management system for the Maryland Early Hearing Detection and Intervention Program. The online data base allows for virtually real time data sharing which facilitates more timely and accurate follow up and improved continuity of hearing health care. **/2013/ The Sickle Cell Follow up program has a new database system that is designed specifically for case managers to increase work flow efficiency to assure children identified in the program receive timely follow up. The data system has built-in features which automate various aspects of both proactive and reactive processes. Electronic forms, letters, and other important documents improve workflow and track the progress of individual cases. //2013//**

## **VI. Reporting Forms-General Information**

Please refer to Forms 2-21, completed by the state as part of its online application.

## **VII. Performance and Outcome Measure Detail Sheets**

For the National Performance Measures, detail sheets are provided as a part of the Guidance. States create one detail sheet for each state performance measure; to view these detail sheets please refer to Form 16 in the Forms section of the online application.

## **VIII. Glossary**

A standard glossary is provided as a part of the Guidance; if the state has also provided a state-specific glossary, it will appear as an attachment to this section.

## **IX. Technical Note**

Please refer to Section IX of the Guidance.

## **X. Appendices and State Supporting documents**

### **A. Needs Assessment**

Please refer to Section II attachments, if provided.

### **B. All Reporting Forms**

Please refer to Forms 2-21 completed as part of the online application.

### **C. Organizational Charts and All Other State Supporting Documents**

Please refer to Section III, C "Organizational Structure".

### **D. Annual Report Data**

This requirement is fulfilled by the completion of the online narrative and forms; please refer to those sections.